THE LIVED EXPERIENCE OF WOMEN WITH ABNORMAL PAPANICOLAOU SMEARS RECEVING CARE IN A MILITARY HEALTH CARE SETTING

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ABSTRACT

The Papanicolaou (Pap) smear is one of modern medicine's greatest success stories. Since its introduction in 1942, this cost-effective procedure has greatly reduced morbidity and mortality from cervical cancer. Despite the effectiveness of this screening tool, patient compliance with treatment recommendations for abnormal Pap smears remains low. This qualitative research study explored the lived experience of women with abnormal Pap smears receiving care in a military health care setting. The purpose was to describe this phenomenon and contribute to existing knowledge, with the intent of understanding the experiences of women with abnormal Pap smear results. A purposive sample of six women who had received abnormal Pap smear results was engaged for data generation. Open-ended interviews were conducted, and transcripts of the interviews were reviewed and analyzed for themes, interpretation, and meaning of the lived experience. Participant's words and descriptions were integrated and provided the foundation of the study. From twenty-seven interpretive data clusters, seven essential themes emerged. The themes included: pre-experience knowledge, facing an abnormal Pap smear result, contextualizing, doing something, negotiating being "more than a cervix", adapting and coping, and sharing. These themes illuminated the essence of the experience as it was lived and facilitated the description of the phenomenon under investigation.

Key Words: **qualitative research** **abnormal Papanicolaou smear** **lived experience** **phenomenology**

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PREFACE

This research was conducted to provide a description of the lived experience of women with abnormal Papanicolaou smears receiving care in a military health care setting. It was designed to add to existing knowledge and facilitate greater understanding of the phenomenon, so that clinicians may implement strategies to improve women's understanding and compliance with surveillance and follow-up recommendations.

DEDICATION

To my dad and my mom, I dedicate this thesis. My father, who embraces his dreams and makes them his reality, has uniquely inspired my ambition, drive, and pursuit of meaningful discovery. My mother, who tempers passions with peace, has always had an intuitive way of saying the words I needed to hear, just when I needed to hear them. I thank you both for your strength, commitment, and unconditional love.

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It is with awe and humility that I recognize the many people who have inspired, encouraged, and made possible my success in this endeavor.

First, I gratefully acknowledge the women who volunteered to participate in this research project. Their stories are the substance of this study. I am privileged to have had the opportunity to listen. My sincere desire was to adequately transform their lived experience into a text that accurately describes their reality. I hope that I have succeeded.

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A very special thanks is expressed to my friends and colleagues throughout my "lived experience of graduate school." How refreshing they were – ever honest, supportive, and sincere. What strength we found from each other! Thank you especially - Steve, Brian, James, and Susan. You have been the greatest cheerleaders.

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Introduction

The use of Papanicolaou (Pap) smears, as a screening tool for cervical cytological abnormalities, has been well established. Current guidelines recommend that all women over the age of 18, and younger, if sexually active, need to be screened regularly for cervical cytological changes that may be predictive of cancer. This screening standard is well known in the American medical community, and there is little deviation from this recommendation (U.S. Department of Health and Human Services, 1998). Likewise, there is universal agreement among health care providers that an abnormal smear should result in follow-up care and potential treatment. The problem begins here.

Background

The Pap Smear

The Pap smear is a screening test of cervical cells. Once the Pap specimen has been obtained, cytologists and/or pathologists interpret and report the results, using standardized terminology from the widely published Bethesda System (Foulks, 1998; Kurman, Henson, Herbst, Noller, & Schiffman, 1994; McMeekin, McGonigle, & Vasilev, 1997; U.S. Department of Health and Human Services, 1998). The terminology and definitions standardized by the Bethesda System provide a diagnostic tool that assists providers in making appropriate follow-up recommendations. Follow-up recommendations, ranging from annual Pap smears to surgical intervention, are based on the degree of cytologic and pathologic abnormality.

Tracking of Results and Follow-Up Failure

As recommended by the U.S. Department of Health and Human Services (1998), most facilities have a system in place to track Pap smear results, notify women of abnormal results, and advise them of follow-up recommendations. However, many women do not return for follow-up care as directed and are at increased risk for cervical cytologic changes that may lead to undetected and untreated malignancy. Many studies report follow-up failures to be as high as 30%-80% (McKee, 1997; Melnikow, Chan, & Stewart, 1999; Rajaram, 1998; Stewart, Buchegger, Lickrish, & Sierra, 1994). These numbers are concerning when considering the morbidity and mortality associated with cervical cancer. Howell, Chen, and Concato (1999) report that in the United States, there are 16,000 new cases of cervical cancer annually and 5000 deaths, ranking this malignancy as the third most common of the female genital system.

The pathophysiology and clinical course of cervical cytological abnormalities have been well delineated. Fairly standardized language, terminology, and treatment algorithms have evolved (McKee, 1997). Facilities have refined their office protocols and tracking systems to follow women with abnormal Pap smears. Elaborate computerized databases are available to generate automated notification of results. Seemingly, all of the pieces are in place to encourage and facilitate patient follow-up; yet, compliance with treatment recommendations and adequate patient follow-up continue to be a problem of significant clinical concern. There must be more to the story. What is the experience of women with abnormal Pap smears? How does their experience influence their decisions?

Barriers to Follow-Up

Several studies have attempted to identify and address barriers to follow-up (McKee, 1997; Miller et al., 1997; Rajaram, 1998; Stewart et al., 1994). Some of the identified barriers include lack of health insurance, childcare, and administrative problems (McKee, 1997), as well as beliefs, values, fear, and minority status (Howell et al., 1999; McKee, Lurio, Marantz, Burton, & Mulvihill, 1999). However, the identified barriers do not fully explain non-compliance to follow-up recommendations. Furthermore, none of the research has been conducted at a military health care facility; and identified barriers may not be the same in this unique population.

Relevance of the Problem to Nursing

An exploration of the experiences of women confronted with an abnormal Pap smear result and their follow-up decisions corresponds precisely to the definitions of nursing, to nursing practice, and to nursing research. Nursing is caring for and about people. Nurses view people holistically, recognizing that people are more than the sum of their parts and that they respond to health and illness as individuals, in unique familial, cultural, societal, and individual contexts. Health promotion, disease prevention and patient education are the foundations of nursing practice. As a science, nursing pursues understanding of human phenomena in order to discover the means to build upon these foundations. The need for additional nursing research is evident. Despite advances in clinical experience and cytological technology, improvement in patient follow-up rates has not been universal. Something is missing.

This study describes the lived experience of women who are confronted with abnormal Pap smear results. Through a descriptive phenomenological approach, the

reactions and decision making processes of women in a military health care setting who are advised to follow-up for abnormal Pap smear results are explored.

Historical Perspective of the Problem

The Papanicolaou (Pap) smear test has had a significant impact on the reduction of cervical cancer rates since its introduction in 1942. According to McKee (1997) and Foulks (1998), mortality from cervical cancer has been reduced by as much as 75%. The success of the Pap smear is linked to its attributes of being cost-effective, simple, and relatively painless (Foulks, 1998). However, in spite of its remarkably positive impact in the women's health arena, problems surrounding the Pap smear persist. These problems include increasing numbers of women with low-grade cervical cell abnormalities, false reassurance when Pap smear interpretation is inaccurate, and inadequate follow-up care for abnormal Pap smear results.

Increasing Numbers

According to McKee (1997), the number of women with abnormal Pap smear results is increasing. The increases are partially attributable to epidemic exposures to human Papillomavirus (HPV) and the effects of cigarette smoking on cervical cells. This information is corroborated by the Centers for Disease Control and Prevention (1994), which indicated rates for atypical squamous cells of undetermined significance (ASCUS) to be 8.0% of 31,569 women under 30 years of age screened between 1991 and 1993. The same sample revealed rates of low-grade squamous intraepithelial lesion (LGSIL) to be at 9.4% (1994).

False reassurance

Lonky, Sadeghi, Tsadik, Girma, and Petitti (1999) describe limitations of the Pap smear and indicate its potential to under-interpret significant cervical pathology. From sample collection techniques to laboratory interpretation, steps in the collection and reporting techniques may contribute to error. In their study, high-grade lesions or cancer were discovered on 329 of 1784 (18%) of women referred for a single Pap smear with a result of LGSIL. Similarly, high-grade lesions or cancer were discovered on 278 of 3118 (9%) of women referred for ASCUS. These researchers assert that false reassurance occurs at least 33% of the time and recommend aggressive follow-up strategies.

Inadequate Follow-Up Care

The literature is replete with studies that address the issues of poor follow-up care rates for abnormal Pap smear results. The rates, influencing factors, and efforts to improve follow-up care comprise the content of the literature review and will be explored thoroughly in Chapter Two of this study.

Purpose of the Study/Problem

The purpose of this study is to explore and describe the experiences of women confronted with abnormal Pap smear results in a military health care setting. Many factors are described in the current literature to explain why women fail to follow-up as recommended for abnormal cytological evaluations. These include fear, economic concerns, medical skepticism, socio-economic status, ethnic background, lack of child-care, insurance, or transportation, and language barriers, as well as many others (Howell et al., 1999; McKee, 1997, 1999; Melnikow et al., 1999). The intent of this research is to

add to existing knowledge by describing the experiences of women confronted with abnormal Pap smear results. Through this effort, it is hoped that a clearer understanding of their decisions about follow-up care will emerge.

Although some of the factors identified in the research may apply to women in a military health care system, current literature does not address factors that may be unique to this population. These barriers may include spousal deployment, inconsistent health care providers, lack of same-language care providers/educators, access to care barriers, frequent moves and changing availability of medical services, cultural insensitivity, or other, unidentified factors. Certainly, the goal of greater understanding of experiences among women at military health care facilities is a worthy one.

Data do not exist in current literature regarding "no-show" rates at local military facilities, but it is conceivable that rates may resemble those at civilian facilities. From the facility perspective, this is wasted provider/clinic time in a system that is criticized for lack of available appointments. From the patient perspective, the costs are even more significant. Undetected cervical cancer will have many long-term consequences, which will ultimately impact the patient, her family, and the healthcare system.

Research Question

What is the lived experience of women in a military health care setting (who have either sought follow-up care or not sought follow-up care) when confronted with an abnormal Pap smear result?

Justification for Qualitative Methodology

With the exception of few examples, the literature reveals primarily quantitative analyses on the subject of nonadherence to follow-up recommendations for abnormal Pap smear results. These studies only partially explain factors that contribute to patient behaviors; they do not consider holistic perspectives available through the personal interpretations of the women who are faced with abnormal Pap smear results. The data collected have partially addressed the nature of the phenomenon but most have looked to external, tangible factors, rather than to the women themselves and the experience as it is lived by them. Cervical cytologic screening programs are ultimately ineffective if patients requiring follow-up evaluation and treatment are "lost." It seems that in many cases, institutional efforts to promote follow-up and women's follow-up behaviors are at cross-purposes.

Phenomenology

Phenomenological research was the selected research method, as its purpose "… is to describe experiences as they are lived…" (Burns & Grove, 1997, p. 71). Without an understanding of the meaning of abnormal Pap smear results, as perceived by women in their own socio-cultural context, universal follow-up recommendations and strategies are less than adequate. Missing are the rich, personal, experiential data that allow understanding and offer the hope for meaningful intervention. The aim of this study was to contribute to the knowledge base by adding another dimension to the existing literature.

CHAPTER II: EVOLUTION OF THE STUDY

Introduction

This study originated from the researcher's personal experience in managing a dysplasia clinic for four years at a multi-cultural, military family practice clinic in Sasebo, Japan. The researcher observed great variation in the behaviors of women confronted with an abnormal Papanicolaou (Pap) smear result. Emotional reactions ranged from fear, anger, and apathy to acknowledgment and acceptance. The researcher, an active duty registered nurse, had extensive opportunity to counsel patients, discuss treatment options, and follow-up recommendations, and provide support during initial results notification and ongoing follow-up treatment. The researcher often pondered the differences among women who elected to follow-up as recommended, in comparison to those who, in spite of extensive follow-up contact and encouragement, never returned or had a sporadic and inconsistent pattern of follow-up care. The researcher's observations stimulated a desire to learn more about the lived experiences of women confronted with abnormal Pap smear results.

Contributing Literature

Introduction

In order to appreciate the relevance of this research study, it is important to describe the nature of the problem, define care-specific terminology, and establish an understanding of current medical practices. The importance of routine cervical cytologic screening has been demonstrated. It is estimated that the rate of invasive cervical cancer has been reduced by as much as 70% because of routine Pap smear screening (U.S.

Department of Health and Human Services, 1998). Annual health maintenance examinations for women are not complete without inclusion of this simple, inexpensive, and relatively non-invasive screening test. As a screening tool, the Pap smear is considered to be an effective means of detecting cervical cytologic changes. However, the Pap smear has limited diagnostic value, in that it is frequently demonstrated to underestimate the severity of cervical disease (Ferris et al., 1998).

The Pap Smear: Its Limitations

Out of the approximately 50 million Pap smears collected in the United States annually, from 5% to 10% will return with a cytologic finding of atypical squamous cells of undetermined significance (ASCUS) or as a low-grade squamous intraepithelial lesion (LGSIL) (Ferris et al., 1998). Although the need for follow-up is evident among women with these mildly atypical diagnostic categories, provider recommendations vary greatly, ranging from repeat Pap smear to colposcopic examination with biopsy. Mayeaux, Harper, Abreo, Pope, and Phillips (1995) found that simply repeating the Pap smear after a period of time failed to pick up high-grade lesions requiring definitive treatment in up to 73% of women with an initial abnormal smear. Based on their findings, they recommended that all women with any degree of cervical abnormality be followed with colposcopy, endocervical curettage (ECC), and biopsy, for further diagnostic reliability and appropriate management.

Slawson, Bennnett, Simon, and Herman (1994) reached similar conclusions in their study comparing repeat cytology alone to repeat Pap smear in combination with acetic acid wash. Their study also demonstrated an intolerable rate of false-negatives among the cytology alone group. Follow-up Pap smears alone failed to detect high-grade disease

30% of the time among women with a single screen of cervical atypia. Based on their study results, all women with a cytologic report of ASCUS were offered subsequent colposcopy examination in their six-clinic family practice setting.

In spite of numerous study findings advocating aggressive follow-up (colposcopy with biopsy, versus waiting and repeating a screening Pap smear), practice guidelines have not changed in recommending a watch-and-wait approach to follow-up for an interpretation of ASCUS on an initial screening Pap smear. Provider discretion finalizes the recommendation decision, allowing for a range of interpretation and variability among provider recommendations. In a military heath care facility, the potential for variability is great. A woman may receive care from a general medical officer, a nurse practitioner, an independent duty corpsman, a family practice physician, a physician's assistant, or an obstetrician/gynecologist. In military health care settings, there is a great potential for variation among health care providers (who are influenced by resource availability, education, and experience) for follow-up recommendations

Variability among provider recommendations for follow-up is further complicated by evidence that patients' likelihood of following recommendations is influenced by this variability. For example, Suh-Burgmann, Darragh, and Smith-McCune (1998), in their review of provider management patterns, speculated that patients scheduled at lengthier intervals for follow-up are less likely to follow-up as recommended. Provider approach to cervical atypia is usually conservative, as many clinicians view the condition to be minimally concerning and take a wait-and-see attitude toward further intervention (Slawson et al., 1994). Obviously, the variability among provider recommendations for follow-up may leave patients with a confusing range of possibilities regarding their

treatment decisions. The apparent lack of clear, standardized guidelines for clinical providers has the potential for great variability in patient outcomes as well. However, this variability does not adequately explain certain women's failure to comply, when definitive follow-up recommendations are made.

Nonadherence to Follow-up Recommendations

The current literature is replete with studies that attempt to identify the factors contributing to nonadherence to follow-up recommendations for abnormal Pap smear results. Additionally, several viable interventions have been demonstrated to improve compliance rates among certain populations. Why then, does there continue to exist a discrepancy between provider recommendations and actual patient behavior? Indeed, the current literature addresses many of the presumed factors for less than optimal patient follow-up. However, several dimensions have yet to be explored, including determinants of nonadherence among military health care beneficiaries. Furthermore, the data are somewhat inconsistent with regard to generalizing patient attributes that seem to predict follow-up behaviors. The topic merits further research, since failure to follow-up can lead to extreme and devastating medical outcomes for the patient.

Comparison of Relevant Literature

In their study of 202 women at an urban community health center in the Bronx, NY, McKee and colleagues (1999) analyzed barriers to follow-up of abnormal Pap smears in an at-risk clinical population. They studied primarily minority, low socio-economic status patients and conducted their interviews in English and Spanish, as needed. The study included women with a mean age of 30.2 years, with various ethnicities: Hispanics (52.8%), Blacks (34.7%), Whites (6.3%), and Asians (4.1%). They found that younger

patients were at risk for poor follow-up. Teenagers had the highest rate (40%) of nonadherence to follow-up recommendations. Additionally, the study indicated that women who knew and understood the results of an abnormal Pap smear were much more likely to have a colposcopic follow-up (83%) compared to women who did not know their results or believed their results to be normal (59%; P=. 02). Factors determined not to have a statistical significance for follow-up behaviors included provider type and gender, fear about cancer, language barriers, child-care, transportation, and insurance issues.

Miller et al. (1997), in a study of 828 low-income, minority women, barriers to follow-up were identified by 395 women in the study and classified into three domains: encoding/expectancy barriers, affective/emotional barriers, and self-regulatory/practical barriers. The most common encoding/expectancy barrier was lack of knowledge about how abnormal cells develop on the cervix, with 332 women (84%) reporting this barrier. In the affective/emotional domain, concerns about having cancer were reported by 265 women (67%). Finally, in the self-regulatory/practical domain, cost of the appointment and job, school, or childcare conflicts were the most frequently reported by 142 (36%) and 126 (32%) of the women, respectively.

Addressing other than tangible barriers, Lerman et al. (1991) conducted a study to evaluate psychological effects of an abnormal Pap smear result. They compared 106 women with normal Pap smear results to 118 women who were referred for follow-up for abnormal results. The study measured reported frequency of cervical cancer worries, activity impairment, tension, mood ranges, impairment of sexual interest, and impairment of sleeping patterns between both groups. Women with abnormal results had statistically

significant more worry, activity impairment, worse mood, impairment of sexual interest, and sleep impairments. There was no statistically significant difference regarding tension. In this study, the rate of compliance to follow-up recommendations (colposcopy) was 65%.

Qualitative Studies

Case study. Rajaram (1998), in a qualitative case study, explored one woman's reasons for failure to follow through with recommended treatment following an abnormal Pap smear. The researcher attempted to elicit the woman's perspectives on her diagnosis, cancer, etiology of her disease, and treatment, in order to identify the woman's interpretation of her condition. Using the patient's illness explanatory models of cancer and its treatment, the researcher discovered dominant patient beliefs that were thought to be factors in her nonadherence to follow-up recommendations. These included a belief that intervention for an abnormal Pap smear would cause cancer to spread. She also believed, because of strong familial influence, that abnormal Pap smears were a part of her family, passed down from mother to daughter, and that treatments would inevitably fail. Further, this woman believed that it was better to remain ignorant of her medical condition because knowing about it only resulted in mental anguish. Finally, she believed that God would determine the outcome of her illness and expressed skepticism in the medical model of care.

These findings are extremely important when one considers the inconsistencies between these beliefs and the typical provider approach to patient follow-up recommendations, which may or may not be sensitive to the patient's unique illness explanatory models. The findings in this case study were consistent with others studies

that demonstrated lower rates of follow-up among African Americans and other minority groups (Howell et al., 1999; McKee, 1997; U.S. Department of Health and Human Services, 1998).

Adolescents. Another qualitative study by Kahn et al. (1999) focused on barriers to compliance to follow-up recommendations by exploring the understanding and perceptions of Pap smears among adolescent girls. In this study, 15 girls with a mean age of 17.6 years, were interviewed in one of three focus groups of five girls. One group consisted of girls who had a normal Pap smear. The other two groups were comprised of girls who had an abnormal Pap smear, five of whom received follow-up care in the colposcopy clinic and five of whom did not comply with colposcopy follow-up recommendations.

Several items surfaced as likely barriers to appropriate follow-up behavior. Knowledge regarding Pap smears and pelvic examination was poor. Twelve of the 15 girls were unable to distinguish between the two exam types. However, all 15 reported perceived benefits to receiving Pap smears. Pain and discomfort associated with Pap smears were described by 13 (87%) of the girls. Fear of finding a problem or fear of the unknown was identified as a barrier by 11 (73%) of the participants. Participants verbalized that trusting relationships with providers, as well as appointment reminder notices, might result in improved adolescent compliance with follow-up recommendations.

Australian interviews. In a qualitative interview study, Kavanaugh and Broom (1997) studied 29 Australian women to discover how they interpreted the experiences of diagnosis and treatment of their cervical abnormalities. Several themes emerged from

their study. Although women wanted to participate in their care decisions, they found it difficult to get the information they needed from their physicians. They attributed this to lack of physician time, but also interpreted doctors' non-verbal behavior as the intentional withholding of information. This "gatekeeping" by physicians was interpreted as an indication of the severity and seriousness of their condition. Another dominant theme was the threat to womanhood and femininity, which was experienced by some women, whose fears were exacerbated by an inability to see the cervix. In contrast, women who were able to view their cervix, either by photograph or video monitor, were more at ease and reported a sense of attachment and oneness with this previously obscure body part.

Efforts to Improve Compliance

Educational brochures.

Research studies have acknowledged the problem of poor follow-up among certain populations and have studied strategies to improve compliance. For example, Stewart and colleagues (1994) studied the effects of providing educational brochures on follow-up compliance among 108 women with abnormal Pap smears. The researchers examined the medical records of 108 study participants. Fifty-eight of the women had received an educational brochure at the time of scheduling their first colposcopy appointment, while 50 of the women received no brochure. Demographics such as ethnicity, age, socio-economic status, or education were not significantly different between the groups.

Forty-three (75.4%) of the women who received the educational brochure had full compliance 18-24 months after initiation of follow-up. In contrast, only 23 (45.8%) of the women who did not receive the brochure had completed follow-up recommendations at

the same time interval. The difference in compliance was 30% (p=.002). The study did not indicate whether or not the control group received any other form of counseling or patient education. The researchers concluded that educational brochures, with clear recommendations for follow-up, improved patient follow-up rates (Stewart et al., 1994).

Personal contact. McKee (1997) conducted a metaanalysis that summarized the various strategies employed by clinics and individual providers to enhance abnormal Pap smear follow-up rates. Suggestions included structured telephone contact, educational pamphlets, transportation incentives, health-promotion checklists, computerized reminder systems, and certified mailings. Central to McKee's review is the suggestion that personal contact with the primary care provider, or appropriately trained office staff, may allay fears often associated with colposcopic examination. Further, the author indicated that strategies employing personal contact are likely to elicit greater response because they address a frequently cited preference among women patients to have personal contact, as opposed to letters or other forms of communication. McKee also describes the advantage of personal communication as a technique for improving understanding, treatment options, and promoting clarification and reassurance.

Mailings, phone calls, and patient education. In a large study by Miller et al. (1997), patients' adherence to treatment recommendations was evaluated based on assignment to one of three study groups. The study spanned 2 ½ years and looked at the follow-up adherence rates of 828 women. Eventually, 611 were assigned to one of three groups for participation in the study. In one group (n=217), patients were simply sent their Pap smear results by mail, with a recommendation for colposcopic follow-up. This group had an initial adherence rate of 50% (109/217) and a subsequent adherence rate of only 30%

(9/30). A second group was provided the same mailing, but also received one phone call to determine any barriers to follow-up. This group had an initial adherence rate of 68% (147/216) and a subsequent adherence rate of 36% (17/47). The third group received the same mailing, but also received a barriers identification phone call, which included additional telephone counseling to assess patients' understanding about the importance of follow-up and query about specific concerns relating to the appointment or getting to the appointment. In this group, there was an initial adherence rate of 76% (300/395) and a subsequent adherence rate of 61% (49/80). In summary, the study group that employed a personal contact intervention, which included open-ended dialogue, demonstrated greater success in improving follow-up rates.

Summary

In summary, the current literature demonstrates a profound need for ongoing study of nonadherence to follow-up recommendations for abnormal Pap smears. The current literature does not provide an exhaustive, nor conclusive, explanation for follow-up failures. Furthermore, current literature has not addressed the problem in a military health care setting and fails to account for barriers that may be unique to this patient population. There may be costs, barriers, and consequences as yet unidentified in the current state of knowledge on this subject. It is evident that additional information is needed, which is the basis for this study. It is difficult to address the myriad explanations for nonadherence, when so little is known about the lived experience of women with abnormal Pap smears.

CHAPTER III: METHOD OF INQUIRY

Research Design – General

Introduction

A descriptive approach was used to address the phenomenon in question: What is the lived experience of women in a military health care setting when they are informed of an abnormal Pap smear result? In this chapter, the qualitative research design is explained. The phenomenological approach to data generation is described. The specific processes for sample selection, data generation, and participant protection are outlined. And finally, the components of trustworthiness of the study are elaborated.

Qualitative Approach

In the qualitative method of inquiry, the researcher's purpose is to gain insight through the discovery of meanings, by improving comprehension of the whole. From a holistic perspective, qualitative research explores the depth, richness, and multiple realities of complex human experiences. Through the gathering of insights, qualitative research aids in the development of nursing theory. The qualitative approaches, derived from various philosophical orientations, share several common features, including the idea that phenomena occur in context, which gives phenomena meaning, and that meanings are not static, but rather change over time, in different contexts, and for different people. The qualitative researcher is comfortable with the idea of multiple realities and meanings and seeks insights that are uniquely available from this perspective (Burns & Grove, 1997).

Although qualitative research unfolds through a variety of research designs, there are common attributes among the paths of discovery. Streubert and Carpenter (1995) outline six common characteristics of qualitative research: a belief that phenomena occur in context and that the research inquiry is conducted so as not to influence or disrupt the natural context in which a phenomenon occurs; an acknowledgment of multiple realities; a resolve to discover information and allowing for method and data generation practices to evolve appropriately based upon phenomenological understanding; a focus on participant's perceptions – allowing their real life story to be the reality explored; conceding that the researcher is a participant in the research and that the inquiry, by its nature, will have a subjective quality; and that the style of reporting will reflect the depth and complexity of the phenomena through conveyance of participants' stories, words, and perspectives of the people who truly own the experiences.

Phenomenological Method

The phenomenological approach in qualitative research has its foundation in philosophy. An integral component of the approach is the acceptance of multiple realities. A starting point for understanding this is made when one ponders the concept of reality. What is real? Is it tangible? Is it sensed? Is it malleable? Morse (1994) explains, "Experience of things or phenomena include sense perception (seeing, hearing, touching, tasting, and smelling) and other phenomena, such as believing, remembering, anticipating, judging, intuiting, feeling, caring, loving, imagining, and willing" (p. 127). Dynamic and complex, the lived experiences of individuals are the multiple realities, from multiple perspectives, upon which, qualitative and phenomenological research is based.

Ray (1990) justifies use of the phenomenological approach or method as "… more adequate for the study of human beings wherein the situated meanings of human experience can be understood" (p. 173). In nursing, the science of caring, where holism is valued, phenomenology affords the nursing profession "… the opportunity to study and research an almost infinite variety of human and environmental phenomena" (Munhall & Boyd, 1993, pp. 52-53). Phenomenology contributes to the body of nursing knowledge by revealing the nature and meanings of human experience. According to Van der Zalm and Bergum (2000), the practical application of this in nurse-client interactions is that phenomenological understanding "… alters action….Phenomenological knowledge reforms understanding, does something to us, it affects us, and leads us to more thoughtful action" (p. 213).

Data Generation - General

Data generation in phenomenological research is achieved primarily through observation and in-depth interviews. The goal is to transform the lived experience of study participants into language, conveying an accurate description of their subjective reality and its meaning. The obligation of the researcher during data generation is to transform participant's words and descriptions into comprehension of the original experience, as it was lived. This is necessary because no one can ever experience another's reality (Streubert & Carpenter, 1995).

Because data collection will involve in-depth retrieval of information, the researcher must be aware of his or her influence on the interview process. Study participants must be completely at ease sharing the most private of details. Even a researcher's personal characteristics, such as age, race, or sex may interfere with a participant's openness. For

these reasons, it is appropriate for researchers to ask or determine whether or not they are the appropriate people to elicit a study participant's experiences (Streubert & Carpenter, 1995).

Qualitative Interviewing Techniques

Interviewing techniques in the phenomenological approach are familiar to most nurses. The use of open-ended, clarifying questions encourages participant expression without leading the interview. Because the interview is a shared experience, in which the researcher is an active participant with genuine interest, participants are regarded with respect, attentiveness and active listening. It is important for participants to feel comfortable, at ease, and protected. Although the purpose of the interview is data generation, study participants must never perceive the interview as an interrogation (Streubert & Carpenter, 1995).

Rubin and Rubin (1997) clearly outline the steps involved in the qualitative interview process. In structuring the qualitative interview, the researcher relies on three types of questions – main questions, probes, and follow-up questions. Main questions are developed prior to the interview and serve to begin and guide the interview. Main questions may be altered during the course of the interview and are guided by what is learned from participants through the generation of data. When an answer to a main question lacks detail, or greater depth is required, a probe elicits longer and more detailed explanations or examples. Probes serve the additional purpose of letting the participant know that the researcher is truly interested in the story being told. Finally, follow-up questions pursue revealed themes, clarify meaning and validate interpretations. Follow-

up questions cannot be developed in advance, because they originate as a result of participant responses to main and probe questions.

Rationale for Method

In the broadest sense, the phenomenological method is appropriate to explore phenomena requiring holistic consideration. In considering this method, researchers should ask whether there is a need for greater clarity of a particular phenomenon and whether the description of lived experience is the best source of data for the phenomenon under study. If there is little or nothing published on a subject, or it requires deeper analysis, phenomenological methodology may be an appropriate design. Additionally, if the topic under investigation is concerned with the meaning of human life experiences, phenomenological research methodology should be considered (Streubert & Carpenter, 1995).

Ray (1990) clearly delineates the necessity for phenomenological methodology in nursing research. As the definition of nursing science has evolved to include concepts such as "… nursing as a human science, nursing as the science and art of human caring, clients as experiencing persons, and the importance of the context in human interaction" (p. 173), an alternative method of inquiry has been recognized, with which to investigate nursing interests. As the study of lived experience, phenomenological research uses description and reflection and seeks fuller understanding and meaning of identified phenomena. Van der Zalm and Bergum (2000) further assert that the phenomenological method is especially appealing to nurses, who are seeking meaning in their own practice, because phenomenology imposes a non-reductionistic approach to human understanding.

Research Design – Specific

Introduction

The purpose of this study was to explore the lived experience of women faced with an abnormal Pap smear result receiving care in a military health care setting. Although current literature exists on this topic, with an emphasis on non-compliance to medical follow-up recommendations, virtually none of the literature focuses on women's lived experience in relation to their follow-up decisions. Additionally, no research on this topic was discovered with respect to military populations. The lived experiences of these women are most appropriately studied with a phenomenological approach for reasons clearly stated by Streubert and Carpenter (1995): "Just as caring for only part of the patient is inconsistent with nursing practice, so too is the study of human beings by breaking them down into parts" (p. 34). In other words, simply telling a woman that her Pap smear results are abnormal, and to follow-up next Tuesday may not be adequate. The goal of this study was to add depth and clarity to existing literature, as well as to provide a foundation for further research.

Data Generation Procedures

Study Population

The population for this study consisted of women receiving care at a military treatment facility who had been notified of an abnormal Pap smear result and had been instructed to receive follow-up care.

Criteria for Sample Selection

Patton (1990) describes purposeful sampling in qualitative research, as opposed to quantitative sampling methods. In qualitative research, the sample is selected purposefully, with depth of information being the focus of the inquiry. In purposeful sampling, participants are selected intentionally because of their information-rich, lived experiences. Because the focus is depth, versus breadth, the sample size may be relatively small. "In-depth information from a small number of people can be very valuable, especially if the cases are information-rich" (p. 184). The researcher's goal was to select information-rich cases that would help to shed light on the phenomenon in question. Ray (1990) suggests that the sample size in phenomenological research may vary but that five to ten participants will generate significant data. In a qualitative study, where depth of the explored phenomenon is of great importance, sample size tends to be very small (Burns & Grove, 1997).

Six women were included in this study. Criteria for inclusion included:

1. History of an abnormal Pap smear, with instructions to receive follow-up care at a military treatment facility. Participants may or may not have adhered to follow-up treatment recommendations.

2. Willingness to discuss the experience of receiving an abnormal Pap smear result.

The sampling method was purposive, using facility-identified women who potentially met criteria for inclusion in the study. The dysplasia clinic nurse who was responsible for notifying patients of their abnormal Pap smear results determined the first criterion for inclusion. The second criterion for inclusion was indicated by the patient's

positive response to an invitation to participate in the research study. The only criterion for exclusion was an age less than 18 years. The phenomenon under investigation was the lived experience of women confronted with an abnormal Pap smear result. The purposive sampling method described generated information-rich data from women who met the outlined inclusion criteria.

Interview Preparation

Initial contact of potential participants was made by an introductory letter from the dysplasia clinic coordinator of the military treatment facility (see Appendix A). This initial mailing insured that patient confidentiality was protected and that the researcher only had access to interested research participants. The letter briefly described the nature of the proposed research and invited interested participants to contact the researcher directly by telephone. Non-interested women were instructed not to respond. Thirty letters were mailed in order to generate an adequate number of interested participants. Additionally, a generalized handout was available in the OB-GYN clinic waiting room, so that any interested women could contact the researcher directly (see Appendix B).

When interested participants responded by telephone, eligibility was determined based upon the previously outlined criteria for inclusion. The researcher described the research purpose and participant welfare considerations. The researcher answered any questions. If the potential participant continued to express interest in the study and willingness to participate, arrangements were made for an interview appointment at a time and location that were most convenient to the participant. Although the length of time between the notification of an abnormal Pap smear and arrangement for an interview

varied among participants, all data that were generated during the interviews were considered valuable and were of interest to the researcher.

Interview Process

At the time of the interview, prior to data collection, the Consent for Voluntary Participation in a Clinical Investigation Study (Appendix C) was completed. Through the voluntary consent, participants acknowledged the research purpose and procedures, their right to refuse to answer any question, and their right to withdraw from the research project. Any questions about the research were answered. Additionally, participants were given contact information if they had questions about any element of the research project. Each participant was provided a copy of the consent form.

Data were collected using in-depth unstructured interviews. The interviews were recorded using audiotape. Interviews were expected to last between thirty to sixty minutes, but were allowed additional time if the participant expressed a desire to continue relating her experience and if the investigator recognized that new or information-rich data were being generated. Interviews took place at the mutual convenience of the participants and the researcher regarding time and location. An interview guide was available to the investigator for initiating and guiding the interview. The guide included eight open-ended main questions:

1. Tell me how you were informed about your Pap smear result.
2. Describe the first thought that went through your mind when you learned of the result.
3. How have your thoughts changed from that moment to now?

4. What kinds of things (if any) did you do to try to understand what your results meant?

5. Tell me what you understand about your result now.

6. How did the experience make you feel?

7. If you had questions about your result, what resources were available to you at the facility? From family? From friends? Other?

8. Is there anything you can identify about the experience that made it good/bad or made you more/less likely to follow-up according to the recommendations you were given?

Interviews were recorded using audiotape, and field notes were generated following the interviews. The nurse investigator, the author of this study, conducted all of the interviews. Participants were provided contact information in the event that they needed to contact the investigator.

Protection of Study Participants

The proposed study met the standards established by the Uniformed Services University of the Health Sciences and the military treatment facility's Institutional Review Boards (see Appendices D and E). Approval was obtained by each. Potential participants were provided an explanatory letter from the dysplasia clinic coordinator describing the study and inviting voluntary participation. The letter described the interview process, protection of privacy, and directions for responding if interested in study participation. Women who were not interested in study participation were

instructed not to respond to the invitation and remained anonymous to the researcher. No additional mailings or invitations for participation were made to non-interested patients.

Confidentiality of study participants was maintained throughout data collection and management procedures. Audiotapes of interviews were coded numerically, one through six. Only the researcher knew which participant was assigned the numeric code on the audiotape. Audiotapes were transcribed by a paid, professional medical transcriptionist. The transcriptionist was counseled about patient confidentiality, proper storage of tapes, and management of computer files. The transcriptionist was instructed and agreed to return all data materials, including tapes, transcripts, and disks. She was instructed and agreed to delete all transcripts from the hard-drive of her computer. When they were not being used for data processing, audiotapes and transcripts were stored in a locked file in the office of the principle investigator. At the conclusion of the research project, all tapes, transcripts, and any other data collection materials were turned over to the Clinical Investigation Department of the Military Treatment Facility for permanent storage.

Additional considerations

There was no penalty for refusal to participate or for subsequent withdrawal from the study. None of the participants refused to participate or withdrew. In exchange for participation in the study, participants were offered researcher-provided information and teaching, as solicited by participants, regarding abnormal Pap smear results, follow-up recommendations, and options for follow-up care. None of the information was in conflict with provider-recommended follow-up. Additionally, referral resources were made available by the researcher, as needed, in the case of potentially upsetting interviews. The researcher recognized that the exchange of information during data

generating interviews might have influenced participants' decisions to seek follow-up care.

Data Analysis Procedures

Transcript Management

Data analysis in qualitative research requires time, energy, reflection, critical thinking, abstraction, and creativity as the researcher moves closer toward understanding and describing with words the truths of explored phenomena (Hoskins, 1998). To that end, data analysis in this study required intense review of the interview substance and content in a search for underlying themes. The participants' own words were an integral component of data analysis and theme interpretation. Within 24 hours of each interview, the interviewer reviewed each tape and made written notations. Tapes were transcribed as soon as possible, within two weeks of the interviews. The investigator reviewed and compared the written transcripts with the original tapes. Corrections were made. Transcripts were edited to delete names or other identifying elements.

Data Processing and Analysis

Preliminary data analysis occurred during the process of interviewing and data generation. Frequently, probe and follow-up questions were based on the investigator's initial ideas about the information provided. Using words, rather than numbers, the qualitative researcher relies on thoughtful skills in analytic reasoning, moving from concrete statements to more abstract synthesis (Burns & Grove, 1997). Reflection, discussion, and interpretation were an ongoing process, using feedback regarding interpretation from participants, as well as mentoring from researchers skilled in

qualitative data analysis. Extreme care was taken to interpret data without the bias of the researcher's preconceived ideas, values, or beliefs. Personal reflection was required in order to "bracket" any personal bias and reduce its influence on data interpretation (Hoskins, 1998).

Steps, for phenomenological data analysis, as outlined by Patton (1990), include horizontalizing data, grouping data into meaningful clusters, a delimitation process, and enhancing developed themes. The final step is in the development of a "structural synthesis" (p. 409). At the conclusion of data generation, all data are "horizontalized" for review, meaning that the data are arranged for examination with each element having the same relevance, weight, and importance as any other. Next, data are grouped into meaningful clusters, with identification of emergent themes. During this step, the delimitation process removes data that are irrelevant, repetitive, or overlapping. Finally, during structural synthesis, the essence of the phenomenon is revealed, and the true meanings of the experienced phenomenon are described. For this study, steps in data analysis occurred as outlined.

Trustworthiness

Scientific rigor has been linked with the worth of research outcomes and is valued in terms of research critique. Qualitative research has frequently been criticized for lacking scientific rigor. Burns and Grove (1997) attribute this criticism to the practice of judging qualitative research with rules used to determine rigor in quantitative studies, and assert that different rules must apply. Trustworthiness in qualitative research persuades the audience that "… the findings of an inquiry are worth paying attention to, worth taking account of" (Lincoln & Guba, 1985, p. 290). Common criteria for the consistent

evaluation of qualitative research are outlined by Leininger (1994). Discussed here, five of these criteria were applied to this research in order to demonstrate trustworthiness of the data generation and interpretation.

Credibility

The first criterion is *credibility*, which is the truth, as study participants experience it (Leininger, 1994). The believability of the study, its credibility, is established through prolonged engagement, observation and participation with study participants. Credibility, likened to internal validity by Lincoln and Guba (1985), is enhanced additionally by triangulation, a technique purported to improve the credibility of a study. Triangulation offers an attempt to verify information by employing different sources, methods, investigators, and theories to analyze data (Lincoln & Guba, 1985). In other words, multiple perspectives and different approaches serve to strengthen analysis of the content.

Confirmability

Next, *confirmability* is achieved through notation of thematic repetition or direct (objective) observation of evidence (Leininger, 1994). Confirmability is addressed by restating and affirming ideas with study participants or other investigators. Lincoln and Guba (1995) address confirmability issues through inquiry auditing. As a fiscal auditor would audit accounting data, an inquiry auditor would analyze the research methods of the phenomenological inquiry and attest to its dependability. For the purposes of this study, credibility was strengthened by inquiry auditing by the investigator's research chair and committee members.

Meaning-In-Context

Thirdly, *meaning-in-context* implies that the investigator must manage and interpret data holistically, in the context of the lived experiences of the participants (Leininger, 1994). Sandelowski (1986) emphasizes the unique nature of contextual meaning in qualitative research, asserting that, "… qualitative research emphasizes the uniqueness of human situations and the importance of experiences that are not necessarily accessible to validation through the senses" (p. 33). Certainly, one way to meet this criterion was to seek validation of meaning directly from participants, a technique that was employed in this study during data generation.

Saturation

Another criterion is *saturation*, which refers to fully and comprehensively knowing a phenomenon, achievable through an approach that emphasizes depth. Redundancy and duplication of themes, ideas, and expression are good indicators of meeting this criterion (Leininger, 1994). The investigator may be assured that saturation has occurred when participants convey that there is no more detail that has not yet been shared and when the details take on a redundant or repetitive quality among participants. For this study, the goal was to fully explore the phenomenon under investigation and convey with accuracy the lived experiences of the six study participants.

Transferability

Finally, *transferability* is the possibility of application of research findings to another similar context without loss of meaning. The goal is not the generalization of study findings. Consequently, transferability is useful to explore phenomena in similar contexts

and environments (Leininger, 1994). Regarding transferability, Lincoln and Guba (1985, p. 316) state that the obligation of the investigator is to provide the rich, detailed, and thick descriptions of an identified phenomenon, leaving the decision about whether findings are transferable to those who would chose to apply the findings to another context. In this study, the effort was focused on providing detailed and thorough descriptions of the lived experiences of women confronted with an abnormal Pap smear in a military health care setting. There was no attempt to generalize findings to other populations, settings, or contexts.

Summary

The purpose of this study was to explore the lived experiences of women confronted with an abnormal Pap smear result in a military health care setting. With the use of open-ended interviews, this phenomenon was explored during the data generation component of this study. The goal was to obtain rich descriptions of participants' lived experiences in order to more clearly understand and describe the phenomenon. Data were analyzed using recognized methods for qualitative research. The researcher made every effort to enhance the trustworthiness of the study through identified means and intense committee review.

CHAPTER IV: STUDY FINDINGS

Introduction

This chapter details the findings of the research study, including a description of the sample and analysis of the data. Careful reflection and review of taped interviews and transcriptions were made. The transcripts were read and re-read, allowing for depth of understanding and recognition of emergent themes. After tape and transcript comparisons were made, verified, and deemed accurate, data elements were identified and horizontalized from each of the written transcripts, meaning that no element was considered more or less important than any other. Elements were then organized into meaningful clusters or groups, from which essential themes were derived.

Description of the Sample

There were six participants in the study. All of them were women who had had at least one abnormal Pap smear and were receiving care in a military treatment facility. The women ranged in age from 32 to 64 years. The minimum education level was a bachelor's degree; three had master's level education, and one had earned a doctorate. Several of the women had experienced more than one abnormal Pap smear, with initial abnormal results dating as far back as 22 years ago or as recently as six months ago. Three of the women were career active duty military while the other three were military family members. Each of the women had a vivid recollection of her personal experience and a willingness to share the most enlightening details.

Essential Themes

The data elements were organized into 27 clusters, from which seven essential themes were identified (see Table 1). These themes together illuminate the lived experience of women with abnormal Pap smears receiving care in a military health care setting. The goal of this chapter is to detail their experience in their own words so that the meaning of their experience may be revealed and known. The seven themes include: pre-experience knowledge, facing an abnormal Pap smear result, contextualizing, doing something, negotiating being "more than a cervix", adapting and coping, and sharing. Although by literary necessity, the themes are listed and arranged in a sequential order, it is critical to appreciate that many of the themes occur simultaneously, recur frequently, and that the experience, influences, and is influenced by, the context of a woman's life.

Pre-Experience Knowledge

Pap as cancer prevention. Women know why they are getting annual Pap smears. For most, it is a conscious decision that they make for their own health. They comprehend community education efforts regarding Pap smears. In women's health, the Pap smear is one of two things that women understand to be a health necessity. Their knowledge provides a foundation and context through which they later interpret and process a subsequent abnormal result.

> But I think it was more of a preventive measure to make sure that you didn't have cervical cancer or some kind of – you could catch it early on and deal with it immediately if there was a cancer developing.

> Cervical cancer – they were an early detection for cervical cancer.

Table 1

Interpretive Clusters and Themes that Reveal the Lived Experience of Women with Abnormal Papanicolaou Smears Receiving Care in a Military Health Care Setting

INTERPRETIVE CLUSTERS	**THEMES**
Pap as cancer prevention Paps and mammography Before the abnormal result	Pre-Experience Knowledge
Results notification Alternative explanations and denial Guilt Fear	Facing an abnormal Pap smear result
Playing out scenarios Fertility Career Relative impact of an abnormal result	Contextualizing
Seeking information Pap language Personal control and accountability/ empowerment	Doing Something
Pain Imagery Compartmentalization Paternalism Partnership	Negotiating being "More than a Cervix"
Time in follow-up Anticipation and worry Hoping for normal results Supportive relationships	Adapting and Coping
The "*livid"* experience Catharsis Helping Others	Sharing

Paps and mammography. The Pap smear, like mammography, can detect a cancer in its earliest stages so that definitive steps can be taken. Many of the women in this study compared and related the two exams. The Pap smear, and having one done annually, was viewed as an insurance policy against cancer.

> I think my feeling about that has always been that I do the annual Paps and annual mammogram and annual physical – that kind of stuff. I've always kept up with that so that if there is a problem I can deal with it early on – and I've been – I come from more of a preventive mode. And if there is something, then you deal with it early on and it's treatable, generally.

> If you listen to the dialogue that's put out about women's health, there's only two things that – if you talk to a woman on the street – that she probably has some awareness about women's health: it's get a mammogram and get an annual Pap, because those are very important.

Before the abnormal result. Despite the fact that women are aware of the reasons for getting an annual Pap smear, and motivated by favorable outcomes afforded by early cancer detection, few have ever stopped to ponder, "What if…?" It is as if the insurance policy – faithfully going to get the annual Pap – provides some sort of immunity against ever actually having an abnormal result. None of the women in this study had ever considered what an abnormal Pap smear result would mean to them, until it happened.

> I assumed they'd always be normal. I didn't know what the next step was…I was young. I was invincible.

> Oh, I know what they're for. But it's one of those – they've always been normal, and when they weren't normal, it's usually just because you have a yeast infection or something and so you get it and you go on. But I wasn't in the risk group yet. I was still too young. I wasn't worried about it being the possibility of cancer yet. It was just something you do, like you get your 5-year physical. It's just a routine. It's like you put on your safety belt. Yes, you know that you do it to protect you, but you're not thinking about that every time you put it on. It's just something you do. Why do you brush your teeth? Do you think every time you brush your teeth – Oh, I'm

> keeping myself from getting a cavity or you're putting fluoride on them or just – It's something you do because it's the right thing to do. Because you'll find out if something does come up. But you're not thinking "what if?"

Facing an Abnormal Pap Smear Result

"I now pronounce you husband and wife." "It's a GIRL!" "You have been selected for promotion." "You've won the lottery!" "Ma-Ma, Da-Da." Some words and phrases are never forgotten. They mark critical moments in life, junctures that signify history, accomplishment, opportunity, and change. "You have an abnormal Pap smear result" is no exception. From the moment the words are spoken or read, perceived and recognized, lives take a turn, and evolution is inevitable. Facing an abnormal Pap smear result is the second essential theme revealed in this study. The descriptions that follow illuminate this theme as the lived experience is revealed.

Results notification. Every woman who has had a Pap smear has had the experience of waiting for the results. Typically, a form letter or pre-printed post card of some sort arrives in the mail at some future point in time - or it does not. Women describe their thoughts on those post cards and other results notification methods:

> I just remember receiving – I believe I received a notice in the mail that I needed to come back and have a second Pap done, and I did that….It was a check mark on a card kind of thing; and I think when I called back, they probably – if I remember correctly – probably said it's nothing serious, but we just need to follow up and make sure that it's nothing serious, and that was just over the phone.

> It was pretty much just dumped on me. I had to have some other tests done at the same time; and so I had to go in to get the results on those and they said, "Well, everything looks great, except your Pap smear came back bad."

> It came as a letter where they had things checked; and the dynamic of that is it takes six to seven weeks before this comes in the mail…and so it comes and on it is

> something that – it says that it's – and it's in the and/or language. We're not sure what it is, but it's and/or and you need to come back….
>
> I have an enormous amount of education. I really do. I really do understand almost everything I read…so I'm not scared of any of this stuff, but I have to go and look up these words on the Internet….It's Greek to – I've got to believe it's like "ab" and "normal." That's as far as you can read because it's your body and you've been told since you've become a woman that Pap is the way to stay healthy – not to get cervical cancer. You've got to do your Paps. And so you can't come back to somebody and say, "This is the bowling alley and you're the red pin – you've been knocked down, so…" You can't do that. And I didn't have the sense of *you* before at all because I never…I'd get the same letter and the first one is – you get the smiling happy face and "see you in a year." And I never paid any attention to any of that before…. It is a scale. It is a scale. I mean – have you ever seen these letters? It is a scale…You're happy – you're not really happy – we're really unhappy…
>
> …that seems to be the standard military thing to send a postcard, and I think it's terrible because you don't always get postcards. They tend to get lost in the mail or they get bent up or ripped apart or smeared if it rains – and the ink smears if it rains and you don't know what it said to begin with…which block was X'd or checked….Some of them were folded but then the tape gets ripped off or they're folded over and stapled and the staple catches in the U.S. Postal Service's machines and it gets ripped apart. Like this one got ripped when it came through….Why can't they just take the computer printout, fold it up, and put it in an envelope and stamp one of your labels on it or something, and have me address an envelope instead of address a postcard?

Alternative explanations and denial. Although study participants were knowledgeable about the purpose of Pap smears as a screening tool for cervical cancer, when faced with an abnormal result, they considered cancer among several possible explanations for an abnormal result. A prevalent thought was that a technical error was to blame. Study participants were not hesitant to posit that their abnormal Pap smear result was likely due to laboratory error or a flawed specimen. Conversations with medical facility personnel may have provided this explanation or minimized other potentials. Denial was also identified as a barrier to seeing the truth and accepting an abnormal result

> Well, I'm trying to remember what they told me and that's why I try to keep records so I can go back and refer to them because I don't always remember what the explanation was. But I think there are various reasons you could have an abnormal, that there are abnormal or atypical cells that need to be evaluated. Sometimes there's just – I guess there could be a mistake – yeah, those were the two main reasons that I remember them telling me about…it could have just been that the lab made an error, or that there was a false positive.

> And at that time, I had another Pap smear done and that one came back normal. So, being in denial, I said, "Oh, that's the correct one." And so I just went with the normal one and ignored it for another year – year and a half….So at first it was – I dealt with it in a serious fashion and then went totally into denial. So that when it came back fine the second time, I just completely ignored it and pretended like the first bad one never happened.

> I remember being really, really irritated about that because I was a department head on the ship. We had an underway schedule…we're *doing* things and this was a real annoyance to me because it was very inconvenient…because at that point I figured – so what, so you get an abnormal one. It's probably a yeast infection or something because – or they messed up the slide, or it was too thick, because when I was in college, sometimes you'd get ones like that…I just thought, "How annoying that they can't do this stuff. Don't they realize I'm active duty? I'm on the ship. This is not convenient."

Guilt. Though not as prevalent as some of the emotional reactions to an abnormal Pap smear result, guilt about personal decisions was revealed. The participants in this study were and continue to be quite responsive to medical follow-up recommendations. Each of them was cooperative and assertive about her own medical needs. However, when reflecting upon the experience, feelings of dissatisfaction and regret about personal choices were apparent for some.

> Everything checked out except that my Pap came back bad again. And this time it was a Class II. And so at that time, they wanted to do the colposcopy and biopsies. And when they did that – which is a yucky procedure – what they found was that the limits could not be seen. And so now I know that if I had taken care of it the first time, I could have just been cryozation [sic], freeze and scrape, and be done with it. Now it had progressed on to where I had to have a conization done of my cervix….I just felt so stupid. It was like, "Uhh! Why did you let this much time go by?"

> Because as it was, I was late….And so I felt like, "Oh, God, I can't believe that I let this go like that when it should have been taken care of a year and a half earlier and it would have been a much easier fix than what it was going to have to be now.

Fear. Universally, women had fear when they were confronted with an abnormal Pap smear result. Levels of fear ranged from a little bit of nervousness and anxiety to consumption with worry about cancer, death, and altered hopes for the future. In some cases, participants' fears were addressed, and reassurance and counseling were offered. In others, fears were unacknowledged or rejected and the women felt as though they were left to decipher information on their own, occasionally with increasing panic and worry.

> I think – I think it kind of scared me. 'Cause I'm pretty conscientious about my health and I think I was a little bit nervous about that – a little bit anxious, and I called right away to schedule a follow-up. We were also in the middle of infertility counseling and treatment at that time, so I think I was afraid it might affect my ability to proceed with that….But I don't think I got a lot of counseling either time. It was kind of like this is just routine. Sometimes, well, you have an abnormal Pap for some reason….So I think my fears were pretty much allayed just with that first phone call. This is probably something that's going to be okay, but I do need to follow-up on it and just make sure that everything's okay….I just always feel that if there is a problem, the sooner you can identify and treat it, the better your chances of survival.

> Oh, I was just devastated. I'm like – "Oh my God, no, please no, not this!"…I was terrified…terrified. It was explained to me that it was like pre-cancerous, like there was something unusual about the cell activity. It wasn't actually cancer, but it was just not right. I was like, "Oh my God! 'not right' is just as bad as cancer… 'pre' means a harbinger to…" I didn't know any different and I just felt like it was *this* or *death*….It was awful. It was really awful.

> I thought he must have seen something really bad. And so I asked him. I said, "Well, how bad do you think it is or do you know?" And he said, "We'll just have to wait until the biopsies come back." Which, from the patient's perspective, you're sitting there thinking, "Oh my God! I'm gonna die!" It was just horrifying. "Oh my God, I'm gonna die." I cried for hours that night; I was so upset. I was so upset. I can still remember wandering up the hill to the car and just sitting there in the car, not being able to drive home because I was just – I was so floored.

> But then, what really – when it hit me hard was after we finished and I was sitting in his office and he came in to write up the stuff for my medical record and to talk to me about the test results and everything and when we would get the stuff back. He very – and to this day I remember him saying – he's sitting there while he's writing, and he said, "You really don't have anything to worry about because you're young and because you've been getting annual Paps. The worst this can do is that this will come back as being cancerous, and we'll have to do a hysterectomy, but you really don't have anything to worry about." And I just burst into tears because that was when it was like just hit me in the face: "You don't have anything to worry about. We'll just do a hysterectomy." I mean, that was all I heard. And I'm sitting here thinking, "I've been married for four years. I plan on having kids in another two years; what do you mean you're gonna take my…" I mean it was just…I just burst into tears and I said, "You know, how can you say that?" And that's when he looked up at me and said, "What do you mean?" And I said, "I planned on having children." And I just thought that was so strange and I still to this day think that's so strange. I have never had any of the other doctors along the way be that brusque about something like – that to me was so important. But I guess that was because he was a specialist…and that's what he dealt with. He thought of that as not a big deal, and I guess I was ill-prepared for not having realized the importance and just how bad things were or could have been. All I heard was I might not be able to have kids.

Contextualizing

When faced with an abnormal Pap smear result, women very quickly play out possible outcomes in their minds, considering worst case scenarios and visualizing many potential ends. For these women, this was a way to manage bad news, place the experience in a personal context, and consider the possible ways in which their lives would be affected by the result. Often, this was an immediate response, with almost reflex-fast decision making and instinctual reactions. Frequently, this occurred before the women had obtained any information about the details of their abnormality or the relative seriousness of their cytology results. Many assumed the worst and only asked questions later. Many factors influenced contextualizing, including sense of empowerment and control, an ability to obtain needed information, personal relationships, and career considerations.

Playing out scenarios. Instantly, upon learning of an abnormal Pap smear result, many of the women envisioned possible outcomes, including cancer and hysterectomy. The women described this response as a way of managing the news. In other words, if they could face the worst possible outcome outright, they felt certain that they could deal with any actuality. At this point in the experience, none had sought further information about her results or treatment options. Visualizing possibilities was an immediate response.

> I wasn't married. And so I really didn't have any sense of doom and gloom. I quickly – I think I look at things where as – when something is going wrong, you quickly look at what the worse course outcome could be and then you register that and then you walk it back. And so – once you've accepted the worst that can happen, then you can focus on…well, let's just resolve what's happening – because I can handle what the worst is so I'm not scared of it.

> I really had to think about what was important and was it more important to me – what were the risks – 'cause then I did the "what ifs" – what if everything comes back okay? Okay, fine and go on. If it comes back and I have to have surgery; if it comes back and I need to have a hysterectomy; if it comes back and I need to have chemo or radiation…what are the different levels that it can be and how would we proceed given each of those, and what will it do to my career; what will it do to my family…pursuing the options….I even had one of my sisters agree that she'd be the surrogate mom if I needed somebody.

> If it came back positive for cervical CA [cancer], stage IV squamous, or whatever….I have myself already having a hysterectomy. I have my surgeons picked out and everything. I knew what surgeons I want, who I want to do my anesthesia, what kind of post-op pain – I'm always hopeful that it wasn't as bad as it – you catastrophize – think the worst. So, it's never the worst. It could be but usually isn't.

Fertility. For many women, a perceived threat to fertility was the most prominent concern in their life context. An abnormal Pap smear result was viewed as a likely or potential barrier to bearing children. Even if fertility wasn't a current issue, women speculated on their future ability to have children and worried about the effects of an

abnormal Pap smear result. With the biological clock ticking, women who had chosen to wait for children now questioned their decisions.

> So, I think being older now, still being in the process of trying to have a baby, going through IVF [in-vitro fertilization] now – all of that made me a little more concerned. Being concerned about how it's going to affect fertility – and maybe a little more concerned because I'm older – could this really be a cancerous situation….It's anxiety-provoking when you're trying to get pregnant, thinking – okay, if there's a problem, then they may say to me, "You can't do this [IVF] because the drugs you're gonna need to take are gonna exacerbate this condition and you have to – you have to stop, so you're not gonna be able to pursue this. That was my number one fear is that I'm not gonna be able to continue in the IVF program. And number two is that I may have cancer.

> I wasn't married. I didn't have any children….I always wanted to be a mom….infertility is one of the things that could definitely happen….I was thinking that maybe I wasn't going to be able to have kids and how awful that would be….I'm really fortunate that I have a wonderful son, another baby on the way, and everything is going along great – because, I mean, I could have easily ended up sterile…lobbing off the top of your cervix is not a good thing…it makes it very short and it could be incompetent.

> I was concerned with fertility at that point. I want to have kids… when I even said something to him there, he was very – I don't remember his exact words about what his answer to me was – but I remember that he was very – he put me off. It was basically, "How can you think about having kids; we're talking about your life." 'Cause I said something when I was crying. I said, "You know, you've basically just told me I may not be able to have children. And I am young and I am married and I plan to have a family. And he said, "You shouldn't be worried about that and thinking about that right now. We need to think about you staying alive." And I just – to me, at that time, where I was in my life, and my relationship with my husband, and that we were talking about when we were gonna start a family, that to me was just the most horrible thing he could say….But it wasn't just mortality; it was the idea of reproducing too. It was that – Wow! I've been pushing it off and saying I wanted to wait until after 30 and wait 'til I had finished doing my sea time and now that may be taken away from me because I made the wrong decision.

Career. For women who were employed or had active careers, an abnormal Pap smear result presented issues in terms of privacy, time away from work for follow up, and even guilt about being a female with female problems. Military careerists had

personal feelings about not burdening anyone with their medical issues, but also had an unmet expectation that their care would be facilitated better because of their active-duty status. They struggled with thoughts about being career-minded females in an environment that hasn't always been supportive of females in male-dominated roles and careers. They didn't want colleagues or supervisors to be able to use their personal health issues as a point upon which to formulate opinions about their work contribution and availability. They very much felt like cervical health, because it is unique to females, is viewed differently from heart health or musculoskeletal health and consequently is subject to more judgment and scrutiny.

> I probably have some trouble balancing….but a lot of things were rolling at the same time, and this was certainly one of them, and as you know, it's no mean trick to show up and do this each time. I can think of just about any other medical procedure that I would care less about – would have no impact on your psyche – as this one….Which is the whole idea….I work for a three-star [military rank], and I work through his executive assistant when I'm in and out, so it's like my titles to my E-mails got to be – think about the time you're away for this stuff – got to be, "Where am I now?" I have a lot of control in what I do, but I'm also very self – what's the word – conscientious about what I'm *supposed* to be doing. But it got to the point where he would come up and say, "How are you?" It would be like, "Well, I'm doing okay, but I'm not gonna have the discussion with you as to why I'm doing okay."

> But I have a true sense that active duty have some sort of priority in military medicine life. And I don't have a great appreciation of that. I mean it isn't the impact – when you're trying to balance – and I'll bring up the aspect of women in the military. You're trying to balance the credibility of "we can do everything you can do better" kind of thing and yet, you're being held hostage by this system that isn't seeing you….the person that I work for – he can get seen whenever he wants – immediately, for anything. I can't get seen unless I go through the gatekeeper and then I can't get seen – so I've got almost an hour commitment to get an appointment and then to come to the place where they can provide the service – it can take half a day easily.

> Time magazine this week has a big article about the Navy released some study that women go to the doctor more than men on ships. There will always be cases where they're trying to say women need something special or it's like they look for

> them….It's just one of those things. And when women went aboard ships, it's one more thing that can be brought up as – that's different.
>
> I was supposed to stay flat on my back for three days to a week and I was the chief engineer on the ship so, I mean I *had* to work….But I did stay down the rest of that afternoon – but for the next two or three days, I stayed pretty much in my stateroom so that I was somewhat down, but I still had to be at work, cause we were getting lit off, getting ready to get underway, and – you gotta be there….I did have good guys. I worried….that thinking right there is what crossed my mind because I felt kind of guilty….It depends on your CO and your XO, what they're like….when I had my first pregnancy, I lost my first child, and the CO that I had at the time…his first comment to me when I told him that I was pregnant was, "This is terrible timing." It varies from person to person. Some of them are not so supportive. They see everything as something that – "Oh, it's because you're a woman and you just can't hack it."

Relative impact of an abnormal result. In terms of life issues and relevant life events, women place an abnormal Pap smear result high on their list of vividly memorable and potentially life-changing experiences. All of the women in this study had experienced marriage, childbirth, and other comparably "important" life experiences. When asked how an abnormal Pap smear result fit, in terms of relevance and importance, women agreed that the experience was comparable to other noteworthy life milestones. For some, it was the first time they seriously considered their own mortality.

> It's up there, 'cause it could be a life-changing event. I'd say about a 7 to 8.
>
> Oh. It's a chapter. But it's clearly this little mini-saga…
>
> I had to still work and go about my daily routine, but it was always niggling in the back of my mind, like – I don't know if it made life a little sweeter thinking, "God, I could have cancer…"
>
> It's definitely one of the biggest impacts. I mean, I'd put it at a 10. Because that has – and having what I had to go through about, because of that, changed my way of thinking at that point. I mean, I was – it made me realize – first of all, it made me stop and realize, you don't get to live forever, because I could be dying.

Doing Something

Shortly after learning of an abnormal Pap smear result, many women took an active role in trying to gain additional information. Women who felt that they were assertive about their own health care needs pursued a variety of resources for gaining information, clarification, and a greater understanding of their test results. On the other hand, some women felt very much alone in their fear and emotional responses, powerless to ask questions or get any information, other than the directions they were given. A sense of empowerment, accountability and personal control was a prominent factor identified by the women who sought additional information and an active role in their plan of care.

Seeking information. Within the experience of dealing with an abnormal Pap smear result, women encountered a range of emotions and feelings. Suddenly, they were facing the unknown, confronted with a test result that few had even considered. Without exception, women felt like they needed more information than was provided on the post card that came in the mail or the telephone call explaining that your Pap result is "bad." Some were able to access information and were satisfied with the answers and explanations that they received. Some were comforted by the reassurances of others – medical personnel, relatives, and friends. Some were simply left with more questions and unanswered frustrations and fears.

> And I talked about it with some – two of the other women that I worked with because several of us went to the same doctor. And so I think more just informally talking to friends and then with my husband…asking him some specific questions and I think he probably said – which he usually does say when I have questions – he answers them as best he can and then he refers me to books that he has so that I can look further if I need to….I got the information from [the clinic nurse]. I have to say that whenever I speak to her and I have questions, she's good at answering that. And

> both of the people I saw there – both providers – were good at answering my questions.
>
> I'm sure I talked to a couple of close friends. But, I mean, they really didn't have – and I talked to my sister. But they really didn't have any more information than I did. And I guess I was just too busy…and maybe part of me really didn't want additional information – like I was already overloaded as it was. If it were to happen now, I would want to know everything.
>
> I have an older sister and she's my confidante as far as – someone I would discuss things with. They're no-holds-barred discussions. And from a woman's perspective, she's the only one right now that I would talk to….I think she in some sense led me to be as aggressive too because her idea was – "Well, when are you going to get in? When are they going to see you?"
>
> What you can do is you can put in 'cervical cancer' and you get back what that dynamic is and what the treatment is for that diagnosis. But I'm not there. I'm just in this never-never land of why is this happening? Where is this coming from? And I started asking questions like, "Could they be coming from the uterus? Is there something else going on we don't know about?" And they said, "No."….They all get together; they look at the slides and they try to figure out, in a bigger picture, "Why is this person being so difficult to treat? Now, we haven't done any treatment; but, what's going on? Why is this happening? Where is this coming from?" So, I have some expectation – I think that they'll try to be able to explain it to me…."We need to come to closure…you have to figure out what's wrong. This can't be that hard."
>
> I looked it up. I'm Internet capable and I'm sure I asked a few – some of the doctor – enough to get direction on where to go and what to find out about. And I have a sister who – both she and her husband are RNs with BSs in nursing and so I called and asked her about it and talked to her and started finding out just how many women I knew that have bad Paps, abnormal Paps, and so, all of a sudden it started sounding more common….But I was reading everything I could about the 'what ifs.'

Pap Language. While sorting through the emotions, seeking information, and trying to interpret the meaning of an abnormal Pap smear result, women are bombarded with a new vocabulary of terms. The language of Pap smears and follow up treatment plans is technical and difficult to interpret, even among experienced health care providers. It is virtually foreign to the lay community, even among well-educated women. Several

descriptions of women's experiences were colored by "Pap language." Without context and background knowledge, few would have a clue about what these women were trying to describe.

> The results from what I remember said just a very borderline…but however that's been determined, I was told it's just borderline abnormal. It doesn't look like this is a significant problem, but it's just far enough over the line that we normally follow up on these…I think it said "abnormal" or if it said "atypical" or something…and I asked them….what does this mean? "Well, you know, you're borderline – you're just kind of over the line there, but we prefer to err on the side of caution…" Cause I'd never heard I think the word 'colposcopy' before.

> It wasn't clearly cancerous, but that he definitely thought it was pre-cancerous and that some of it might be "Stage whatever" – and I don't even remember now because I didn't understand the rankings of it….But he told me that he would call it cancerous except that if he put it down it would always be on my record that I had cancer and he didn't want to put me at risk…so if he called it 'pre-cancerous' then they could take care of it and it would all be taken care of….It was like he was saying, "Well I see some cancerous cells"…negative in the sense of bad – that there were some bad cells….It was like he was side-stepping…

> …and he gave some options. He said, "We can do the cryosurgery, but I can almost promise you there will be scar tissue and we'll have to do it more than once, and we'll probably end up with problems." He said, "You know, by doing the punch biopsy, that frequently gets all the bad cells anyway and so you may already be fine from where we did the biopsy, because that is a method of treatment to just do the punch biopsy." But he said, "What I'd really like to do is something which is new (which now isn't new at all); it's an electro, electrolized, electrized – I forget the word…" Anyway, it's a loop that has electric current going through it and we'll just literally burn off a section of your cervix and your treatment is a cure.

Personal control and accountability/empowerment. In their efforts to "do something," about their abnormal Pap smear results, women demonstrated a sense of personal accountability, expressing a belief that they could influence the outcomes of their exams through early intervention, treatment, and follow-up. They associated active personal participation and decision making with an expectation that their cervical

abnormalities could be and would be treated promptly and effectively. Several expressed a requirement to be especially assertive about their own needs, having to advocate for themselves, lest they be deprived of vital information. For those less empowered, the experience of receiving an abnormal Pap smear result and complying with treatment recommendations left them feeling frightened, alone, frustrated, and unable to acknowledge options and alternatives.

> Nobody wants to hear that they have cancer. I have friends that have dealt with breast cancer and with cervical cancer and some of them have really had a difficult time. Others have come through fairly well…there's a wide range. Some people have gotten in early and been treated and really haven't had any issues after that. Others have had along struggles and it's really been a battle. And I think some of those folks didn't get in early enough. Maybe they were in denial or didn't want to follow up because they were afraid.

> And I was so young and inexperienced and stupid that I didn't know any better than to question – than to say, "Hey! You can't treat me like this!" or ask for a different doctor…I thought I had to deal with him because that's who they referred me to. So I didn't know that I could just say, "I don't want to deal with this person. I would like a different doctor."….I was just naïve, inexperienced, didn't know any better…

> I am very aggressive in health care. I mean, I don't wait for things to mature. If I think something's wrong, I'm gonna get seen. I'm not gonna wait. So, when you say – Well, I'm going to get my Pap and then you have one that comes back abnormal, then my immediate response is – I'm gonna shake the tree. I'm gonna go find out what's going on because I'm not going to be a statistic. I'm not going to be – "Oh, if you had come in two months before, maybe we would have caught 'X'"…not knowing what 'X' was.

> My sense was that I was not the routine patient. I was not deferring. I was being a little bit – I mean, I'm pretty polite. I don't get angry in tone or manner, but I'm not gonna let stuff go. So, I wanted to understand and I think that was frustrating for her, because she wanted to do what she needed to do and move on, and I probably had a ten-minute window, and I was busting her schedule because I wanted more dialogue. I wanted greater understanding.

Negotiating Being "More than a Cervix"

Throughout their recollections and descriptions of the experience, women with abnormal Pap smear results were able to fully relate all of the factors that influenced and evolved into the reality of their experience. With exceptional clarity, they recalled and described the most vivid of memories. They were extraordinarily lucid regarding the personal details of place, people, tactile sense, visual imagery, emotions, and feelings involved in the experience. They shared everything from the excitement of discovering what a cervix looked like to the satisfaction of being a partner in their health care; additionally, they spoke of paternalism, pain, and the frustrations of not being heard. Emerging from these descriptions was the prevalent theme of the cervix being compartmentalized, isolated, and somewhat detached – not physically, but conceptually – to the extent that the cervix, not the woman, was the focus and concern.

Pain. Very few women experienced pain during any of the gynecologic experiences surrounding an abnormal Pap smear result and follow-up treatment. Many of the women had had repeated Pap smears, colposcopic exams, biopsies, and even the more invasive cryotherapy and LEEP (loop electrosurgical excision procedure) treatments. Most of the women verbalized mild discomfort, but when compared to other experiences (e.g. childbirth) described the pain as minimal. However, this was not true for all.

> You hear people say it's a painful procedure, when they did a biopsy. But I've been through a lot of stuff with infertility, like hysterosalpingogram… so I wasn't real worried about it…And I don't know if they said – if they suggested to take Ibuprofin beforehand, or if one of my friends suggested that. I may have done that. And then when he said, "I'm just gonna put a little anesthetic here…" then I didn't feel anything.

> And I remember being really scared. And, I mean, the colposcopy itself was nothing… all they're doing is looking…nobody told me how much the biopsies were gonna hurt….And he said to me, "Well, they don't hurt." And I looked at him, and I was like, "Well, when have you had this procedure before?" Don't tell me they don't hurt. I just had them done a week ago. They hurt like hell! It was like a nasty, wrenching cramp each time – like a clench and a cramp…I think they took three or four at that time. The second time, he took eight….And then the pain started. 'Cause it was very painful – very painful. And they wouldn't give me – he wouldn't – the doctor wouldn't give me anything. It was like burning, like somebody had taken a hot poker and gone up inside and just like – well, my cervix was raw…at the time it was just – it was awful.

Imagery. Without exception, women were able to recall graphic details about the visual images and sensory perceptions that were relevant to their experience. Some descriptions left little to the imagination; the recalled details were vivid and shared with expressive animation. These images and feelings were as much a part of the lived experience as any other and influenced women's perceptions of the care they received, the competence of the staff, and the empathy of those involved in their care. The imagery left indelible impressions upon these women and influenced their experience as it happened, as well as the content of their current memories.

> I couldn't stand him. He was – I mean, I could hear him outside the door badmouthing me to his assistant….He was saying that he was sick and tired of this particular clinic referring people over to him and…he just really didn't want to deal with me or my case or anything….He was just a butcher. I felt like a piece of – a slab of meat – cutting through the conveyor belt to be fixed. Heal with steel. I just felt like he didn't look at me as a person at all, or he wouldn't have talked outside of the room about me within total earshot – like I couldn't hear him….As far as I could tell, [I was] just a piece of meat – another – just a long line of surgeries that day – just another one.

> And it was done under local with the Valium cocktail. And there was actually a mirror on the ceiling up above which was really cool 'cause I got to see what they were doing…and then when they were finished, it was so funny – I remember him showing me the sample 'cause I wanted to see what they had taken out. It looked like a pig snout. It was like, "All that came out of me?" And you could see where the punch biopsy had been, and I mean, it was probably ¾ of an inch to an inch-long

> chunk….What shocked me was that it was so big. I mean, you think of your cervix as just this little hole somewhere and – if somebody had asked me to describe it, I would have probably described it as like your pinky. But this is like the size of a quarter and it's like a pig snout. And that's what was so cool. It was actually seeing it and saying, "Wow! – Wow, that's really cool!"

Compartmentalization. The collection of a Pap smear sample is frequently part of an annual comprehensive well-woman exam. When an abnormal result occurs, a woman may be advised to repeat the Pap smear or follow up in a colposcopy or dysplasia clinic. Subsequent appointments typically are problem-focused and do not address any other health concerns that may have developed. For women in this study, isolation of the cervix was evident and, for some, a frustrating dimension of their experience.

Focus on the cervix precluded women from obtaining related gynecologic care without additional visits to another provider. Additionally, close follow-up in a dysplasia clinic seemed to eliminate the necessity for a comprehensive annual exam, which may have allowed other problems to be undetected. For women obtaining specialized cervical care, other essential elements of a comprehensive well-woman exam, such as the clinical breast exam, other screening tests, the bi-manual exam, and any other health promotion activities may have been neglected.

> So, I call up the colposcopy nurse and say….I want to see a GYN doctor – never seen a GYN doctor before. And I didn't understand at this time that you have the colposcopy doctors and they're in a Chinese wall from the GYN doctors – probably doing the same thing, but they don't diagnose, don't talk, don't deal with those other issues…And so she's telling me I can't get where I want to go. She tells me, "You have to go back to your primary care provider and get referred." And I'm just – I'm really unhappy with this….And I wasn't sure what I was gonna do, but I was gonna do something. But she explains to me about this Chinese wall and the fact that they're so compartmentalized that it doesn't make sense to me. 'Cause I think all of this is a GYN issue. I don't think this is – there's no "cervix clinic" that I know of….This is so silly. I've almost been in 19 years and in my field this is not – I mean, I'm a support person. This is not support. I mean, I've bent over backwards to figure

> out people's issues and contacted whoever…personally took it on to try to sort all of this stuff out, and required people that I was involved with to do the same thing.

> Being a member of the colposcopy clinic, every six months I go back for a Pap smear. But that's all it is. It's just that – the colposcopy. They don't do a manual exam or anything. So during this time from early '99 to now, I have been going to the colposcopy clinic, getting Pap smears, no manual exams being done, and I grew this – and I didn't think of it at first – until all of a sudden I'm diagnosed with this tennis ball sized mass on my left ovary…it was just one of those flukey things and I'm thinking, when I go to the colposcopy clinic, there is no exam besides the look at the cervix and the biopsies, if needed….I think that's incomplete…I think that it's incomplete care. I know that it's the colposcopy clinic, but I think that the full examination should be done, because you already have a woman at risk – maybe cervical CA or whatever.

Paternalism. Paternalism was a prevalent feature of the experience for some women. With few exceptions, women trusted the advice and treatment recommendations that were provided for follow-up of their abnormal Pap smear results. Also without exception, they could identify occasions in which they felt that they were partners in health care decisions or, in contrast, when they felt that they were not being heard. In cases where they perceived paternalistic control of decisions, they were less happy about their experience and less likely to report satisfaction or a positive feeling about the experience.

> I guess when I asked him about it and kind of pressed him on it – and all of that's just the difference in doctors. Some doctors are better at the bedside manner, or whatever you want to call it, than others are. And he just seemed to be the, "Hey, I'm busy – I'm taking care of it – You don't need to know all that. I'll let you know what you need to know" kind of person…I don't like it and I don't tend to be with those kind of docs, but I understand it…

> I could have gone through the same hell that I went through the first time where I was terrified, and nobody would talk to me, and nobody would tell me what was going on…it just seemed like everyone at that hospital was pretty cold….they went through the bare minimum of what they needed to do to get you on the table…. I really think a lot of it is a trickle-down theory. The first doctor was a cold, unfeeling jerk, and so that trickled down to everyone around him. And so they were all kind of brusque and cold and unfeeling and like that.

Partnership. Women are not hesitant to share their opinions about health care facilities, providers, and an assessment of their experience. They are quick to offer comparisons of their own "good" and "bad" Pap smear experiences and the details of each. Women who were satisfied with their care and expressed positive feelings about their follow-up plan described their experiences in terms of a partnership with their doctor or health care provider. They felt as though the climate was conducive to getting their questions answered. They felt as though people had time to address their needs and a genuine concern for their health.

> I have to say that the care that I have received at Bethesda has been good…they were very good about making sure that you knew what you needed to do and why you needed to do it…I think that did make me want to follow-up because they seemed interested and concerned about my care and my condition and – like they were working with me. We were working together for my benefit. I feel like they give you the information and you need to act on it, but they provide the information. And when you call and have questions, they answer the questions.

> I prefer – I much prefer the doctors – and actually I like the nurse practitioners better than the docs in most cases because they're much better at working with the patient…Because my feeling is – I could be the doc there too if I had chosen to go to school. It's not like there's something special or a magic wand that they can wave. It's just a matter of education and training and some retain better than others…Their ability to do their job is based on their communications with me and knowing my body. So, it's not something magic. And so I prefer to have the kind of doctor that will relate with you and to tell you…

Adapting and Coping

Once an abnormal Pap smear is acknowledged, women may be engaged in a variable period of time in which they are advised to have more frequent Pap smears, possibly colposcopy exams, and the potential of biopsies and/or surgical intervention. Women did

not generally have an appreciation of the amount of time that they would be spending in follow-up for an abnormal Pap smear result. During this time, women faced fear and anxiety about recurrent abnormal results. They expressed frustrations about not getting definitive treatment while a wait-and-see approach to care was followed. They hoped for and expected their follow-up Pap smear results to be normal. Adapting and coping over time emerged as a prominent theme in the experience.

Time in follow-up. Women may spend two to three years in a close surveillance program for an abnormal Pap smear result. This is a substantial commitment and one that may not be fully appreciated or readily understood by women who are urged to comply with follow-up recommendations. It may be particularly difficult for women in a military health care setting, where mobility and disruption of care may be the reality for the patient and the provider. The women in this study were able to comply with follow-up recommendations. However, their feelings of frustration and perceptions of inconvenience were a real consideration for them.

> I think I was laid up for a few days and it started to get better. I think I went back to work at the end of that week, I'm pretty sure. I don't think I even took a full week off. And then life got back to normal – well, semi-normal – because after this then every three months I had to have a Pap for like a year. And then it went to every four months, and then it went to every six months. And I remember it was like a really big deal when I got to wait a whole year before I had to go back again…a couple of years before I got cleared…

> And I know this had a factor in my own impatience for resolution…Right now it's been every three months….But I think that I need to have that answered…. I'm not coming in every three months….It's been a long time. And my previous experience was we zapped the cells. So, maybe, I don't know, medicine has changed and that's no longer an acceptable practice to make resolution. But I'm really somewhat frustrated with the idea that there's this gray zone and I can't…I need to come to closure because I have things I want to plan for.

Anticipation and worry. Many women dread their annual Pap smears. However, they overcome their discomfort because they recognize the importance of the exam and rationalize that one hour or so every year is a relatively small sacrifice for their health. Generally, they anticipate normal results. However, for women with an abnormal result and an increased frequency of repeat exams, substantially more time is spent planning for, scheduling, keeping the appointment, and waiting for the results of the Pap smear. Once an abnormal finding has been identified, subsequent exams may bring renewed worry and anxiety while waiting for results.

> I didn't want to go through that again….And on pins and needles every single one too. I thought – "Oh my God, is it gonna be back? Is it gonna be back?"….Because every time I have one done, it's always in the back of my mind – Is it gonna come back bad?

> It wasn't any constant perception – but when you go in for your Pap, it's like – "Well, I wonder if it'll come out okay." And after a couple of years where it was – it got to be very routine – then I didn't have much concern about it. I wasn't anticipating any bad news.

> I came back again three months later and had it again, and then I went to six months, and then I did six months times three, and everything was always normal. And then I went back to regular annuals. I wasn't worried then. I still had to wait for the Paps to make sure…I mean, it's, "Okay, did they get it all, or are we gonna have to go through something else?" And I knew that you have to keep doing it because they could come back. But it's the first one that you're still sort of holding your breath – "Is it gonna be okay?" But once that first one was okay, it was like, "Now it's just another routine. It's a little more frequent, but I can deal with this."

Hoping for normal results. Every woman wants her Pap smear to come back with a normal result and a recommendation for annual follow-up. As previously described, most women never anticipate an abnormal result if they have always had normal Pap smears. Simply getting them done provides a sense of reassurance that everything will be fine –

like it always has been. For women who have had the experience of learning of an abnormal Pap smear result, the hope for normal results in follow-up care is a prevalent thought and no less important, even though the possibility for another abnormal result exists.

> Between the first one and the second one I think I was – it's just kind of in the back of your mind. "Is this gonna be okay?" How's it going to affect my health in general, and, at that time, whether I can get pregnant….And now I'm just – I think I'm pretty positive, and I'm thinking I'm just gonna go in and the second one is gonna be fine. I know it's gonna be like the first time when I went in and they put the solution on and there's not gonna be anything that turns white and that needs to be biopsied. It's all gonna be fine. That's my hope, probably my hope more than my expectation.

> I can't remember if it said questionable or what, but it was basically just that…."You need to contact us."…And I also had a voice mail left at work….the phone call one day and the postcard the next day…I figured it was probably a too-thick sample or something like that….'Cause I thought – I have two kids; I haven't had any problems. But I did tell my – I mean I wasn't as naïve. I told my husband – I said, "Here we go again." I feel sure it's going to be nothing because I really think that if it was coming back and it was cancer I would know something somehow. I think I would know. I don't think that it would just be out of the blue like this….intuitive or something. I mean, it just seemed so out of the blue. It just seems like – I've gone seven years without a problem. Why now?

Supportive relationships. The lived experience of receiving an abnormal Pap smear result does not occur in isolation. It is a contextual event with meaning that is defined by a myriad of human variables. Personal relationships were a significant and influential factor in women's interpretation of their results, their emotional reactions, and their coping and adaptation to follow-up treatment plans. Although the experience of learning of an abnormal Pap smear result usually occurred individually, with a telephone call or a post card, it would not be long before significant others were involved with and made a part of women's lived experiences.

> I know that I couldn't have any – there was to be no sexual contact for two weeks. I remember that….I had just met my husband, and we had just started dating at that time, and when I knew I was going into this procedure, I was trying to be very blasé, and said, "Well, you know, I have to get this done and I'm not going to be able to do anything for two weeks, so we'll see you in two weeks." And he was just like – he sat me down and he was like, "No, I want to see you through this." And that's probably why he's my husband today.

> It was definitely life changing because it made me reevaluate what was important, what were the options…my husband was really supportive in that he's the one actually that brought up that if it was that important to me that we have a child, even if my life was at risk, that I needed to keep in mind that there were other options…there was technology….And so then he said, "Well, what if then? What if? Now what's the worst case scenario…You're gonna be okay. They're gonna treat it. You're not gonna be dead. We'll adopt if everything else doesn't work out." And I was like, "Well, that's true. We have talked about that. That'll be okay. I can live with it; won't like it, but I can live with it." And so, by the time I went back to see him in two weeks, I was calm.

Sharing

Women were eager to tell their stories about learning of and dealing with an abnormal Pap smear result. They shared significant details about the experience, including their emotions of fear, frustration, anger, and shock. They expressed their concerns and voiced opinions about the elements that made their experience positive or negative. Some expressed a desire to help others. Others simply wanted to vent feelings of frustration, still seeking clarification and resolution of their own experiences. Several remarked that the sharing of their stories was cathartic and that they hoped the details of their experience might help other women. Six women participated in the study; several others volunteered. The six were grateful for the opportunity to tell their stories and share their experiences.

The "*livid*" experience.

The title of this study is, "The Lived Experience of Women with Abnormal Papanicolaou Smears Receiving Care in a Military Health Care Setting."

Women were invited to participate in the study through an introductory letter mailed directly from the dysplasia clinic nurse in the military treatment facility. The participants were unknown to the researcher, until they called to express an interest in participation in the study. It was evident to the researcher from those initial phone calls that women wanted to share their experiences. They were eager to set up interview times. Many began their stories during the initial telephone contact and were asked to wait until the scheduled interviews so that these important elements could be recorded and generated as data. It was clear during initial phone contact that some participants had current unresolved questions and frustrations that they wanted to share.

> So, I've got other pieces that I'm just – all of this is playing in but I'm also playing into the idea that this is serious. You know, you're supposed to be *treated* [tapping on table for emphasis] if you have abnormal Paps. So, I'm not coming back again to her in three months for her to see if it's better. I now want some sophistication in the process….It was like – life is not good; this is really tough here. And so all of this was just frustrating….So, my sense was – I'm running three abnormal Paps and I have now *had it* with the service….I was having this discussion with my husband about the title of your survey and his line was, "…the *livid* experience of women…", which was good, 'cause I was – I'd had it! I was angry…So, see – when your letter came that was introducing your study, it was like, "I wonder if they're targeting me…it was so apropos!"

Catharsis. None of the participants in this study had an expectation that her experience or plan of care would change in any way as a result of her participation in the study. The study offered no immediate promise of improvement or change in any aspect of health care regarding the collection of Pap smears, results notification, counseling procedures, or follow-up and treatment protocols or recommendations. Participants were fully aware that the purpose of the study was simply to describe the lived experience of women with abnormal Pap smear results in a military health care setting. The invitation to participate provided ample motivation for some women to share their experience.

Many cited a personal benefit of catharsis through interview participation and expressed a positive feeling about the opportunity to share their lived experience.

> And this is cathartic for me because I think that the things that need to be woven into these stagnant letters that come is a de-escalation of the fear, because the only thing that you're told is, "You've got to get a mammogram." Maybe that isn't even as – you've got to get old enough to get a mammogram. But – *Pap is life*, and so if you get an abnormal Pap, that you need to de-mystify – I mean, there needs to be a better way to describe this stuff.…There's got to be some de-mystification…

Helping others. In sharing their stories, women offered relevant advice and counsel regarding their experience. They shared their insights about the importance and impact of their own abnormal results. They wanted to help spread the word about the importance of Pap smear exams.

> I don't even know if people realize just how important it is to get your Pap smear. A lot of people will put it off and put it off and say, "Ugh…" And when I talk to those people in my own life, I usually will just shanghai them, make an appointment for them, bring them physically to the office, and relate my experience to them. A Pap smear is so simple and little. And if it's discomfort at all, it's like two seconds. It is nothing compared to what you could be going through.…It's not something to put off. Just go and do it. Have it done. Don't put it off. And if you get a bad one, follow-up.…I just hope that everybody gets up and gets them done 'cause it's just so scary otherwise. I've never met anybody that actually had cervical cancer, but I wouldn't imagine that it's a very pretty way to go. And pretty needless too.

Structure of the Experience

The lived experience of women with abnormal Pap smears receiving care in a military health care facility was revealed through women's descriptions. Through analysis of the descriptions, essential themes emerged. Together, these themes formed a composite view of the phenomenon under investigation. This composite of the experience was the essential structure and is summarized here.

Before learning of an abnormal Pap smear result, women have knowledge about the Pap smear as a cancer-screening tool. They do not anticipate ever receiving an abnormal result and experience a range of emotions when it occurs. They believe that having an annual Pap smear has a protective benefit, like an insurance policy, and experience shock and disbelief when an abnormal result is revealed. Thoughts such as, "Why me? Why now? I've been faithfully getting my annual exam…" occur. Denial and rationalization provide common answers to this self-dialogue, such as, "It's probably a lab error. It's probably a mistake – it can't be right because I have my exam done every year."

Fear is universal and may produce anxiety and worry about infertility, cancer, and death. Women contextualize an abnormal Pap smear result into their lives, and personal significance evolves through reflection about fertility, career, and relationships. Once they learn of an abnormal Pap smear, women are compelled to do something. During this time, they seek information from friends, coworkers, the Internet, and the medical facility. A sense of personal empowerment and control may lead to frustration if answers and resolution are not readily available. Women develop a new vocabulary pertaining to cervical health and treatment modalities.

During the follow-up period, which may span two years or more, women's other priorities regarding roles, relationships and life events may interfere with the dysplasia clinic's singular focus of cervical health. Other aspects of health may be sidelined or neglected by women who have frequent specialty (dysplasia) clinic follow-up. Each follow-up visit may renew fears and worry as the anticipation of normal results occurs. Women with abnormal Pap smear results have a story that they are willing to tell. In

telling it, they share their lived experience, the depth of its meaning, and the essence of this phenomenon.

CHAPTER V: CONCLUSIONS AND RECOMMENDATIONS

Introduction

This chapter presents a summary of the study, study conclusions, and implications of the study findings. Recommendations for further research are made.

Summary of the Study

The purpose of this research was to describe the lived experience of women with an abnormal Pap smear receiving care in a military treatment facility. A qualitative design with a phenomenological approach was used to interview a purposive sample of six women who had been notified of an abnormal Pap smear result. Verbatim transcriptions of the interviews provided the data substance. Prolonged reflection and analysis of the data revealed essential themes, which conveyed the fundamental structure of the experience. Through their words, a description of the women's lived experience was made, and an interpretation and meaning of the phenomenon were revealed.

The study, although not confined to nursing, is significant to the nursing profession because nurses are instrumental in assessing and responding to patients' health care needs. Nurses provide valuable, individualized counseling and education on numerous health topics, including abnormal Pap smear results. Advanced practice nurses perform Pap smears and many perform colposcopy examinations and other treatment interventions associated with abnormal Pap smears. Nurses acknowledge different levels of education, cultural variations, and holistic considerations among patients. An expanded understanding of the phenomenon contributes to nursing knowledge and

enables nurses to counsel and care for patients from a basis of greater understanding and empathy.

Study Conclusions

The lived experience of women with abnormal Pap smears receiving care in a military treatment facility was revealed through this phenomenological study. Several conclusions are drawn from the findings of this study and are presented here.

Knowledge limitations. Beyond very basic knowledge, women have limited understanding of the usefulness of Pap smears or the significance of abnormal results. Women understand the importance of having an annual Pap smear. For the most part, they understand the Pap smear to be a screening tool for the detection of cervical cancer. However, this basic knowledge does not readily translate into a sound foundation for interpreting an abnormal result. Women who are conscientious about obtaining an annual Pap smear are skeptical about the validity of an abnormal result when it happens to them. They feel cheated out of the protection that they thought they were afforded by regular screening. They may erroneously believe that an abnormal cytology report is the result of a laboratory error. They do not have general knowledge about the risks factors that are linked to abnormal cervical cell changes, the treatable nature of cervical disease, and the relatively low risk of developing invasive cervical cancer when detection, surveillance, and treatment occur early in the course of cervical pathology.

Interpreting abnormal results. Learning of and dealing with an abnormal Pap smear result is a major life event. This reality is not fully understood or acknowledged by nurse and physician providers. Consequently, women may not be able to readily access needed information, counseling, and assistance in interpreting their results and understanding

follow-up and treatment options. Women with this experience have heightened sensory awareness. They are able to recall and convey the finest of details surrounding their result notification, cognitive understanding of the result, emotional reaction, and subsequent behaviors. They fear cancer and death. Anxiety and worry may interfere with accurate interpretation of presented information. The abnormal result is given meaning as it is interpreted within individual life contexts. Factors that influence this interpretation include interpersonal relationships, career, and family planning considerations. Women need a great level of support and assistance in processing an abnormal Pap smear result.

Information needs. Women with abnormal Pap smear results need and seek information to help them understand and contextualize the result. Women frequently access resources other than their own health care provider for supplemental information about their results. They consult the Internet, work colleagues, relatives, books, and friends. Although available information from nurse and physician providers is generally described as helpful, women do not necessarily utilize these as readily available resources. Women seek increased understanding of the unique medical terminology, interpretation of results, and available treatment options. They desire a stronger partnership with their health care providers so that they are empowered to make informed decisions about their health.

Adapting over time. Women may be in follow-up surveillance and treatment clinics for a prolonged period of time after learning of an abnormal Pap smear. They do not have a clear understanding of this monitoring requirement. Mild cervical dysplasia may spontaneously revert to normal cytology without treatment. It may also progress to more pathological disease states. It is necessary to closely monitor cervical cell activity over

time, but many conditions allow for a "wait-and-see" approach. For some women, the wait is almost intolerable. They are on "pins and needles" after every Pap smear. They anxiously await biopsy and Pap results, wondering, "Will it be bad? Will it be worse?" Women do not have a clear understanding of the generally slow nature of cervical disease progression and may be anxious for prompt resolution. Clinical practice standards for mild disease typically take a conservative approach, with monitoring and surveillance, versus definitive, more invasive, treatment modalities. Women do not clearly understand this and may be frustrated by a sense that, despite frequent visits, they have not been "cured."

Implications

Implications of this study are far-reaching and extend beyond the nursing profession. For the purposes of this study, implications fall broadly into four areas: nursing practice, nursing education, patient education, and nursing administration.

Nursing Practice

Nurses are positioned to assist with all aspects of patient care regarding abnormal Pap smear results. They often are managers of dysplasia clinics and may have the most frequent contacts with patients in follow-up. Consequently, nurses have a great opportunity to effect positive patient outcomes. In their practice roles, nurses must provide advocacy for women in follow-up for abnormal Pap smears.

The dysplasia clinic nurse must have a comprehensive understanding of all functional elements of the Pap smear and dysplasia clinic processes. Nurses possessing this 'big picture" perspective can and must facilitate women's navigation of a complex

system which crosses clinics, departments, and disciplines. Patient advocacy is perhaps the most important role of nurses in influencing a positive lived experience for women with abnormal Pap smears. Examples of patient advocacy include: availing educational resources, teaching and counseling, tracking of results, ensuring prompt results notification, facilitating communication, assisting with follow-up scheduling, and procedural assistance. Nurses must use assessment skills to determine patient needs and must be prepared to offer anticipatory guidance throughout the experience of women with abnormal Pap smears.

Nursing Education

Advocacy for women with abnormal Pap smears begins with nurses' understanding of women's lived experience. A woman who experiences an abnormal Pap smear result lacks knowledge that she needs to make decisions. She may worry about the long-term implications of her diagnosis. She may experience emotional instability with sleeplessness, crying, and fear. She may consider the impact of her result on career, family, relationships, and her health. She may speculate about cancer and death. An abnormal Pap smear is a significant, possibly life changing event for a woman.

Nurses and other care providers must be educated about the lived experience of women with an abnormal Pap smear and acknowledge the impact of this experience. Nurses must identify their own learning needs and seek formal and informal opportunities to expand their knowledge about all aspects of the phenomenon. Nurses will readily translate this knowledge into action and foster an environment that is responsive to women's needs. This is caring and advocacy and is fundamentally important to nursing. Nursing education must focus not only on the task-oriented aspects of care, such as

patient tracking, follow-up scheduling, and procedural assistance, but also on the psychosocial dimensions of the experience.

Patient Education

Patient education is an area with great potential and opportunity for nursing influence. Many gaps in patient knowledge were identified during this study and direct the implications of the findings. Patient education is a primary role of nurses, and nurses are uniquely positioned to provide this necessary component of patient care. Nurses are credible, reliable resources and provide invaluable counseling, education, and anticipatory guidance. Many of the study findings relate to patient education issues.

Women need and deserve a great deal of information regarding an abnormal Pap smear result. With an appreciation of the emotional and psychological sequelae that accompany an abnormal Pap smear result, nurses should be ready to assess, respond to, and facilitate patient education and understanding of their result. Women with abnormal Pap smears worry about cancer, medical procedures, fertility, sexually transmitted diseases, hysterectomy, and death. Astute nurses and other providers should anticipate these fears, acknowledge them as normal, and address them early in the patient's experience. Intervention of this kind will take time, but is likely to encourage follow-up in dysplasia clinics.

Nurses and other providers must be prepared to educate women about the purpose and limitations of the Pap smear as a screening tool. Health promotion efforts must continue to encourage annual screening, but additional information is needed. Women need to be informed that regular Pap smears offer early detection of cervical cell changes; indeed, that is their purpose. However, annual screening does not prevent abnormal

results. Women who are interested in health promotion and disease prevention need a great deal more information about the risks of cervical cancer. This information needs to be conveyed early, during pre-adolescent and high school health classes, and reinforced frequently at clinic office visits. Women need more information about the treatable nature of cervical dysplasia and the importance of close surveillance and follow-up for this very reason.

Nurses and other women's health care providers can have an immediate effect on this implication, by simply asking women in the clinical setting, "Can you tell me the purpose of the Pap smear and why you are having one done today?" Beginning this dialogue will allow nurses and other providers to assess women's current knowledge and clarify misunderstandings about the purpose of the Pap smear.

Women with abnormal Pap smears need a clearer understanding at the outset of their experience that follow-up may be frequent and ongoing over a lengthy period. Their information needs vary over time, beginning with a need for reassurance and basic information, to greater depth and understanding of pathology reports, options for care, and follow-up plans. Nurses and other providers have an obligation to be available for ongoing questions, reassessment of information needs, and provision of counseling and information. Women should be provided contact information so that questions and concerns can be addressed as they arise. Women use a variety of resources when seeking information. The informational and counseling services of the medical treatment facility should be as accessible as a sister, a coworker, or the Internet.

The literature supports the findings of this study regarding patient education. Kavanaugh and Broom (1997), in their qualitative interviews of 29 women with

abnormal Pap smears, found that women wanted to participate in their care decisions. However, they were confused about the information provided and found it difficult to ask questions or get information they needed. They found it difficult to understand and absorb the technical language of abnormal cytologic results. Practitioners who were commended were those who answered women's questions and spent time on education and reassurance. Clinic nurses stood out and were viewed as particularly effective in this role. These researchers proposed precolposcopy group education as a way to efficiently provide education and offer an opportunity to answer questions and address concerns.

Another study by Nugent and Clark (1996) specifically addressed the sensory information that patients need in order to understand and prepare for colposcopy. Their study supported findings of this study that the lived experience of women with an abnormal Pap smear is influenced by vivid sensory perceptions. Their study described women's experiences from a sensory perspective, including visualization (of colposcope, table with instruments), tactile sense (pinch and cramp), auditory sense (snipping sound of biopsy), and olfactory sense (the hospital smell or odor of vinegar). Specific guidelines and a model for patient education that involves describing sensations associated with the colposcopy exam were proposed. The role of nurses in educating and preparing patients for procedures was discussed, as well as a resultant reduction in patient anxiety while awaiting the procedure.

Nursing and Administration

Final implications of this study address the need for nursing administration involvement and influence. The procedures for scheduling Pap smear and colposcopy appointments, tracking results, notifying patients of results, providing educational

resources, monitoring clinic no-show rates, and commitment of resources are complex. The opportunities for R.N. leadership in this area are abundant.

Women have a right to know their Pap smear results and the meaning of the results in a language that they can understand. Medical treatment facilities must track and disseminate results in an organized and efficient manner. These two requirements are often at cross-purposes. Post cards and form letters are efficient, but lack sensitivity and empathy – qualities of caring that are of utmost importance in the lived experience of women with abnormal Pap smears. Whenever the result is other than "normal" and "return in one year to repeat your exam," women should be notified by telephone or in person of their results, an explanation of the abnormality, and their treatment options. This allows nursing and physician staff an immediate opportunity to address women's concerns and fears and begin the partnership that will likely encourage adequate follow-up decisions. The patient must be given ample opportunity to ask questions and clarify information. An appointment for additional counseling should be scheduled for women with increased informational needs or anxiety that cannot be fully addressed during initial notification.

When women have a Pap smear, regardless of their cytologic history, they anxiously anticipate notification of results. Women should know when to expect their results at the time their Pap smear is collected and be provided a reliable number to call if the result is delayed beyond the anticipated report date. When women have a history of abnormal Pap smears, they are on "pins and needles" waiting for the result. It is inexcusable for facility administrative issues to interfere with timely notification. Adequate resources must be available to facilitate prompt results notification.

Patient comfort and privacy during all aspects of Pap collection, results notification, follow-up appointments, and treatment procedures is paramount to patient satisfaction and improves the likelihood of partnership and compliance with treatment recommendations. This requires a total team effort, and should include consideration of even the most seemingly irrelevant detail – from word choice, to room décor, to patient draping techniques. Nursing administration must lead the way in this regard, through staff education, provision of necessary supplies, and facility aesthetics.

Women need many advocates in the medical treatment facility. They should be able to access and schedule appointments conveniently. They should be able to get their questions answered. Educated nurses and physicians should have the time to assess information needs, counsel, reassure, and facilitate women's understanding of their diagnoses and treatment options. Multiple teaching methods should be available, including personalized discussion, written educational materials, anatomical and procedural pictures with descriptions, and clarification of each as needed. Nurse administrators must prioritize the importance of patient advocacy and allow providers ample time for patient education and counseling in addition to more tangible interventions.

Research Recommendations

Additional research is recommended. Issues surrounding the care of women with abnormal Pap smear results are many and varied. Especially important are issues dealing with patient and staff education, feasibility of facility-supported interventions to reduce fear and anxiety, and continued expansion and dissemination of knowledge about this phenomenon.

Research that investigates interventions and tools aimed at staff and patient education is necessary. Research recommendations from other studies (Kavanagh & Broom, 1997; Nugent & Clark, 1996) that suggest specific educational methods and tools remain viable. Additional research linking education interventions and anxiety levels or education interventions and compliance rates would also be valuable and add to existing knowledge. Research to study cost-benefit analysis of nurse-managed colposcopy education clinics would help to define feasibility of education programs. Comparison studies with clinics that do not offer nurse-managed colposcopy education would also provide valuable information.

This study described the lived experience of women with abnormal Pap smears. It did not provide comprehensive understanding regarding women's follow-up decisions related to their lived experience. Women in this study were all compliant with medical treatment follow-up recommendations. A similarly-structured study that targets and investigates the lived experience of women with abnormal Pap smear results, who choose not to follow-up with recommended treatment, would be valuable. A gap remains in current knowledge about their experience and the issues that influence their decisions not to follow-up. Facility and provider goals should be directed toward and supportive of research that seeks to improve follow-up rates in colposcopy clinics.

This study revealed the possibility of missed pathology for women who are compliant with follow-up recommendations for their abnormal Pap smear, but may not be getting a comprehensive annual exam as a result. A study that examines the rates of occurrence of missed pathology in patients who are visiting their health care provider

regularly may offer new insights, and demonstrate the importance of primary care follow-up, even while under the care of a specialty provider.

Finally, studies that assess women's knowledge about the purpose of Pap smear screening and it's limitations, known risks for cervical cancer, and available prevention and treatment options are needed. Comparison studies across age, education levels, culture, and socioeconomic status would target specific gaps in knowledge and assist in directing and channeling valuable educational resources.

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LIST OF APPENDICES

APPENDIX A

Date: _____

To: _____

From: Dr. Jane Allen, LCDR, MC, USN
Director, Dysplasia Clinic
National Naval Medical Center, Bethesda, MD

Dear Ms. _____

You are invited to participate in a research project entitled, " The Lived Experience of Women with Abnormal Papanicolaou (Pap) Smears Receiving Care in a Military Health Care Setting" being conducted at the National Naval Medical Center, Bethesda, Maryland. You are invited to participate in this project because you have had at least one abnormal Pap smear at a military health care facility.

The purpose of this research project is to describe the experiences of women who have learned of an abnormal Pap smear result while receiving care at a military health care facility. This study is important because it may help to guide the delivery of care to patients with abnormal Pap smears in military treatment facilities.

If you chose to participate in the project, you will be interviewed by LT Cynthia Kuehner, a Registered Nurse in the Navy Nurse Corps who is pursuing a Master's Degree in the Family Nurse Practitioner Program at the Uniformed Services University of Health Sciences in Bethesda, Maryland. During the interview, she will ask you several questions about your experiences of learning of an abnormal Pap smear result. The interview will be audiotaped. You will not be asked your name or any other personally identifying information during the recorded interview. Your identity will be protected during the study and your responses to interview questions will not be linked to you in any way. The interview time and location will be arranged at your convenience, directly with LT Kuehner, if you elect to participate. The interview is expected to last 30 to 60 minutes.

At the time of the interview, LT Kuehner will provide you additional information about the study and will ask you to complete a consent form, which further explains the nature of the research project. LT Kuehner will answer any questions you may have about the research project and your participation. You may ask any question at any time and may refuse to participate or end your involvement at any time.

If you are interested in participating in the research project, please call LT Kuehner to arrange an interview date and time.

You may reach LT Kuehner at (703) 742-4258.

APPENDIX B

Abnormal Pap Smear?

The National Naval Medical Center is conducting a research project entitled, "The Lived Experience of Women with Abnormal Papanicolaou (Pap) Smears Receiving Care in a Military Health Care Setting."

The purpose of this research project is to describe the experiences of women who have learned of an abnormal Pap smear result while receiving care at a military health care facility. This study is important because it may help to guide the delivery of care to patients with abnormal Pap smears in military treatment facilities.

Are you interested in participating?

If you chose to participate in the project, you will be interviewed by LT Cynthia Kuehner, a Registered Nurse in the Navy Nurse Corps who is pursuing a Master's Degree in the Family Nurse Practitioner Program at the Uniformed Services University of Health Sciences in Bethesda, Maryland. During the interview, she will ask you several questions about your experiences of learning of an abnormal Pap smear result. Your answers and participation will be kept confidential.

If you are interested in participating...

Please contact: LT Cynthia Kuehner, NC, USN
Phone Number: (703) 742-4258

Enclosure (5)

APPENDIX C

Pg 1 of 4
Current Version: 12/00
Project No. #B01-004
Date:

NATIONAL NAVAL MEDICAL CENTER
BETHESDA, MARYLAND

Consent for Voluntary Participation in a Clinical Investigation Study

1. You are invited to participate in a research project entitled, " The Lived Experience of Women with Abnormal Papanicolaou [Pap] Smears Receiving Care in a Military Health Care Setting " being conducted at the National Naval Medical Center, Bethesda, Maryland. You have been invited to participate in this project because you have had at least one abnormal Pap smear at a military health care facility. Your participation is voluntary. You should read the information below, and ask questions about anything you do not understand, before deciding whether or not to participate.

2. The purpose of this research project is to: Describe the experiences of women who have learned of an abnormal Pap smear result while receiving care at a military health care facility.

3. Your participation in this research project will be for a period of one day, during a 30-60 minute interview. The duration of the entire project will be for 6 months.

4. The procedure for this project will be as follows:

For this project, you will be interviewed by a Registered Nurse in the Navy Nurse Corps who is pursuing a Master's Degree in the Family Nurse Practitioner Program at the Uniformed Services University of the Health Sciences in Bethesda, MD. During the interview, you will be asked questions about what the experience of learning you had an abnormal Pap smear result was like for you. You may be asked to describe how you felt or what kinds of thoughts went through your mind when you learned of your abnormal Pap smear result. The interview is expected to last for 30-60 minutes. You may provide as much or as little information as you want. You may refuse to answer any question, and you may end the interview at any time. The interview will take place at a time and place that are convenient to you. The interview will be tape-recorded. You will not be asked your name, your age, or any other personally-identifying information during the tape recording of the interview. You may ask questions before, during, and after the interview.

5. A total of six (6) women are expected to participate in this project.

6. The possible risks and discomforts, associated with your participation in this research project includes: There are no expected risks or discomforts expected as a result of your participation in this project. The only inconvenience will be the time required for you to participate in the interview. If any part of the interview causes unforeseen emotional discomfort to you, you may terminate the interview at any time.

Subject/Patients Initials _____ Date _____

7. The research may or may not help you personally but the results may help the investigator learn about the experiences of women with abnormal Pap smear results who receive care in a military health care setting. The information you provide may be helpful in providing the Department of the Navy guidance in rendering services to women with abnormal Pap smears who receive care in a military treatment facility.

8. This project is not designed to treat any medical condition that you may have, therefore there is no alternative procedure course of treatment that would be advantageous to you.

9. In all publications and presentations resulting from this research project, your anonymity will be protected to the maximum extent possible. The nurse researcher who conducts the interview will be the only person who is able to link your interview answers to you. Your name will not be included on the tape recordings of the interview. The tapes will be labeled with a letter code only. A professional medical transcriptionist who is not associated with the National Naval Medical Center will make transcriptions of the tapes. Copies of the transcripts will be kept in a locked file in the office of the principle investigator while the research is being conducted. When the project is completed, the research materials will be turned over to the Clinical Investigation Department of the Naval Hospital for storage. None of the materials will contain your name. In any publications resulting from this research, a pseudonym (fictitious name) may be used to report interview answers. Any pseudonyms used will not be linked or related to you or your name in any way.

10. You may withdraw from this study at any time without prejudice to your future care. Your withdrawal from this project will not cause you to lose any benefits to which you are otherwise entitled.

11. Any new significant finding developed during the course of the research, which may affect your willingness to participate, further will be explained to you (either good or bad).

12. If you suffer physical or emotional injury or if you should require hospitalization as a result of your participation in this project, immediate medical treatment will be available at the National Naval Medical Center. However, if you require inpatient hospitalization, you will be required to pay the customary fees for subsistence (hospital meals) to the National Naval Medical Center in accordance with standard regulations. It has been explained to you that your entitlement to medical and dental care is governed by federal laws and regulations. Any injury resulting from your participation in this research project will be evaluated and treated in accordance with the benefits to care to which you are entitled under these regulations. You will not be entitled to compensation for injuries or to future medical care as a result of your participation in this project except as may be provided for through these regulations or other remedies available under federal law.

13. Your participation in this project is voluntary and your refusal to participate will involve no penalty or loss of benefits to which you are entitled under applicable regulations. If you are active duty military, you should not be influenced by a higher ranking official and you are not being given an order to participate. Your election whether to participate or not will not affect your military career. If you choose to participate, you are free to ask questions or to withdraw from the project at any time. Your participation may also be terminated by Dr. Jane Allen or the institution. If you should decide to withdraw from the research project, we request you notify LT Cynthia A. Kuehner, NC, USN at (703) 742-4258, to ensure an orderly termination process. Your withdrawal will involve no loss of benefits to which you are entitled.

_____ _____
Subject/Patients Initials Date

14. If you have any questions regarding this research project, you may contact Dr. Jane Allen at (301) 295-2575. If you have any questions regarding your rights as an individual while participating in a research project at the National Naval Medical Center, Bethesda, you can contact one of the Research Administrators, Clinical Investigation Department, at (301) 295-2275. They will answer your questions or refer you to a member of the Institutional Review Board (IRB) for further information. If you believe, you have been injured as a result of this project you may call the legal office at (301) 295-2215.

You certify that you have received a copy of this consent form.

_____ _____
Subject/Patients Initials Date

You have read the information provided above. You have been given an opportunity to ask questions and all of your questions have been answered to your satisfaction.

BY SIGNING THIS FORM, I WILLINGLY AGREE TO PARTICIPATE IN THE RESEARCH IT DESCRIBES.

_____ _____
Patient/Subject Signature Date

_____
Printed Name, Grade or Rank

SIGNATURE OF INVESTIGATOR
I have explained the research to the participant or his/her legal representative, and answered all of his/her questions. I believe that he/she understands the information described in this document and freely consents to participate.

_____ _____
Investigator Signature Date (must be the same as subject's)

_____
Investigator's Printed Name, Grade or Rank

SIGNATURE OF WITNESS
My signature as witness certifies that the subject or his/her legal representative signed this consent form in my presence as his/her voluntary act and deed.

_____ _____
Witness' Signature Date (Must be the same as subject's)

_____
Witness' Printed Name, Grade or Rank

Current Version: 12/00

PRIVACY ACT STATEMENT

1. Authority. 5 USC 301

2. Purpose. Medical research information will be collected to enhance basic medical knowledge, or to develop tests, procedures, and equipment to improve the diagnosis, treatment, or prevention of illness, injury or performance impairment.

3. Use. Medical research information will be used for statistical analysis and reports by the Departments of the Navy and Defense, and other U.S. Government agencies, provided this use is compatible with the purpose for which the information was collected. Use of the information may be granted to non-Government agencies or individuals by the Chief, Bureau of Medicine and Surgery in accordance with the provisions of the Freedom of Information Act.

4. Disclosure. All information contained in this Consent Statement or derived from the experiment described herein will be retained permanently at National Naval Medical Center, Bethesda, Maryland and salient portions thereof may be entered into my health record. I voluntarily agree to its disclosure to agencies or individuals identified in the preceding paragraph and I have been informed that failure to agree to such disclosure may negate the purposes for which the experiment was conducted.

_____ _____
Patient/Subject Signature Date

_____
Printed Name, Grade or Rank

_____ _____
Investigator Signature Date (must be the same as subject's)

_____
Investigator Typed Name, Grade or Rank

_____ _____
Witness' Signature Date (Must be the same as subject's)

_____
Witness' Printed Name, Grade or Rank

APPENDIX D

UNIFORMED SERVICES UNIVERSITY OF THE HEALTH SCIENCES
4301 JONES BRIDGE ROAD
BETHESDA, MARYLAND 20814-4799

December 15, 2000

MEMORANDUM FOR LT CYNTHIA KUEHNER, NC, USN, GRADUATE SCHOOL OF NURSING

SUBJECT: IRB Approval of Protocol **T061CB** for Human Subject Use

In accordance with USUHS Instruction 3201, DoD Directive 3216.2, Section 5, Paragraph E, and the Memorandum of Understanding for Clinical Affiliation between the Uniformed Services University of the Health Sciences and the U.S. Navy Surgeon General designating the National Naval Medical Center (NNMC) as a clinical affiliate, USUHS accepts the review and approval by the NNMC Clinical Investigation Department for the research protocol entitled ***"The Lived Experience of Women With Abnormal Pap Smears Receiving Care in a Military Health Care Setting"*** under your direction. It is requested that NNMC provide this office with human subject use review updates at least annually.

The purpose of this study is to explore and describe the experiences of women confronted with abnormal Pap smear results in a military health care setting. The IRB understands that this study involves the interview of 6 women who have had at least one abnormal pap smear at a military treatment facility. Subjects will be asked to participate in a one-time 30 to 60 minute interview. The IRB further understands that while all interviews will be recorded, subjects will not be asked their name or any other identifying information during the taping.

You are required to submit amendments to this protocol, changes to the consent form, adverse event reports, and other pertinent information relative to human subject use for this project to this office for review. It is your responsibility to maintain an accurate and accessible file of all consent forms of participating human subjects.

If you have any questions regarding human subject use, please call me at 301-295-3303.

Richard R. Levine, Ph.D.
LTC, MS, USA
Director, Research Programs and
Executive Secretary, IRB

cc: Director, Research Administration

APPENDIX E

DEPARTMENT OF THE NAVY
NATIONAL NAVAL MEDICAL CENTER
BETHESDA, MARYLAND 20889-5600

IN REPLY REFER TO

6500
Ser 10C/070
13 Dec 00

From: Commander, National Naval Medical Center
To: LCDR J. Allen, MC, USN, Obstetrics & Gynecology
LT C. Kuehner, NC, USN

Subj: APPROVAL OF RESEARCH PROJECT #B01LHOOOOO-004,"THE LIVED EXPERIENCE OF WOMEN WITH ABNORMAL PAPANICOLAOU SMEARS RECEIVING CARE IN A MILITARY HEALTH CARE SETTING"

Ref: (a) NSHSBETHINST 6000.41B
(b) NNMCINST 6500.2C

Encl: (1) Multiple Project Assurance (MPA)
(2) Consent Form
(3) Guidelines to Executing a Research Proposal

1. Congratulations! You have been granted approval to conduct your research project at the National Naval Medical Center.

2. Your official research project number is B01-004. Use this number on any correspondence about your research project. This will expedite the processing of your requests. Your research project has a completion target date of May 2001 and you are authorized a subject enrollment of 6.

3. Your research project was reviewed per references (a) and (b), and endorsed under the DoD Assurance 40001 and MPA M-1515 for the National Naval Medical Center (NNMC). This proposal will be reviewed during the 14 December 2000 NNMC's Institutional Review Board (IRB), meeting. Enclosure (1) is the MPA that investigators agree to adhere to in conducting research.

4. Enclosure (2) is the consent form that is to be duplicated for subject enrollment.

5. If collection and/or analysis of data for your project are to continue beyond one year, you must submit an annual report for continuation. Federal oversight agencies have found this to be a frequent source of problems during their audits, and have stated clearly that projects that have not received at least annual approval by the IRB of record must terminate activity immediately since they are no longer in compliance. In order for ongoing human subject research projects to be reviewed, approved and processed by the IRB within this time constraint, an IRB member will be assigned to conduct a continuing review audit within the IRB approval anniversary date. This audit requirement is your responsibility and you should contact the assigned IRB member when you receive the reminder.

Subj: APPROVAL OF RESEARCH PROJECT #B01LHOOOOO-004,"THE LIVED EXPERIENCE OF WOMEN WITH ABNORMAL PAPANICOLAOU SMEARS RECEIVING CARE IN A MILITARY HEALTH CARE SETTING"

6. Please note that according to the guidelines provided by the Clinical Investigation Program (CIP) Headquarters at the Naval School of Health Sciences, this project in not considered part of the CIP. Consequently, that office will not provide funding for travel associated with this project.

7. Good luck on your research! Be sure to note your research project's requirements of enclosure (b), which are outlined in enclosure (3). This guidebook provides vital information on such items as your responsibilities as a principal investigator, the required research documentation, the procedure to use when making any changes to your research project, required reports and guidelines for publication. Please do not hesitate to contact the CID staff at (301)295-2275 for any further questions or assistance.

A. H. HARRIS
By direction